

SUPPORTING STUDENTS WITH
PATHOLOGICAL DEMAND AVOIDANCE

by

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Supporting Students with Pathological Demand Avoidance

APPROVED:

A handwritten signature in blue ink, appearing to read "J. Haggart". The signature is written in a cursive style with a large initial 'J'.

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Abstract

Pathological demand avoidance (PDA) is a little-known profile on the autism spectrum that can cause problems for students if appropriate strategies are not used. Most of the strategies used in schools for autistic students do not work for students with PDA, causing an increase in demand avoidance and challenging behaviours. While PDA is increasingly gaining acceptance as a profile under the autism spectrum, it is little known in Canada and as such, schools that encounter PDA children may not know how to best support them. This capstone paper details the differences between typical autism and PDA, and the effects of PDA on the individual's mental health, interpersonal relationships, academic success, and on the classroom as a whole. Strategies that have been shown to be successful with PDA students are described. One of these strategies – declarative language – is suggested as a focus for a professional development workshop for school staff with a detailed workshop plan included.

Key Words: adaptations and modifications, case manager, educational assistant, inclusive education, individual education plan, resource teacher, school-based team, special needs funding, special needs student

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Supporting Students with Pathological Demand Avoidance

Chapter 1: Introduction

Working in the educational system, it is not uncommon to come across a student who does not respond in the way you would have predicted or expected. These students are often the most challenging since they test the boundaries of our knowledge and skills as educators. The role of an educator is one of great responsibility and privilege: we have the responsibility to create safe learning spaces for our students and the privilege of helping them achieve success within our classrooms. When we encounter a student who has barriers to achieving success or who does not feel safe in the classroom, we must seek further knowledge and skills to better meet their needs, or we may find that our approach to these students does more harm than good. This is often what happens with students who have Pathological Demand Avoidance (PDA), a little-known profile on the autism spectrum that few educators in this province are aware of since it is not being officially diagnosed by most autism diagnosticians. Students with PDA have challenges that are often greater than a typical student with autism, and the types of interventions that work for PDA students also differ or are opposite of what works for most students with autism. How educators respond to PDA can have a major impact on whether a student is successful or not in the classroom. Yet, without knowledge of PDA and how to approach students who have PDA traits, educators may not be able to appropriately fulfill their responsibility and privilege to help all students feel safe and achieve success.

In Chapter 1, I will discuss the background to my research problem, detail my research questions, and define key terms that will be used in this paper. In Chapter 2, I will review the relevant literature regarding pathological demand avoidance and autism spectrum disorder (ASD), exploring how ASD and PDA are similar and different. I will detail research on how

PDA impacts both individuals and the classroom environment. Chapter 2 will conclude with a discussion of best practices for supporting students with PDA in schools. The final chapter of this capstone paper will provide practical recommendations for how schools can better support students with PDA, as well as suggestions for further research on this topic.

Background

In the 1980s, British developmental psychologist Elizabeth Newson had noticed a pattern of behaviours in a number of children for whom the diagnosis of “atypical autism” was unsatisfactory. She proposed a new syndrome called Pathological Demand Avoidance (PDA) of which the main defining feature was “an obsessional avoidance of the ordinary demands of everyday life” (Newson, 1989, p. 1). As a profile on the broader autism spectrum, PDA has been slowly gaining notoriety in the UK and other parts of Europe (Gillberg, 2014, p. 769), however it is still little known in Canada perhaps due to its exclusion from the current diagnostic manuals for autism spectrum disorder.

Children with PDA have an overriding sense of anxiety about the perceived demands placed on them. Christie (2007) notes that “this anxiety is largely driven by the child’s perception of demands or potential demands, being faced with failure and not being in control” (p. 7). This high level of anxiety that children with PDA feel can lead to a variety of manipulative strategies to avoid having to face the demands placed on them, such as procrastination, negotiation, or withdrawal, and may escalate to refusal, explosive outbursts, and aggression (Fidler & Christie, 2019, p. 12-13). Walker (1993) found that teachers value compliance with teacher commands and following established classroom rules. Students with PDA struggle with compliance and rules since they are viewed as demands, making them difficult students to handle in a regular classroom setting. As such, many students with PDA

have gaps in their education as they are moved from school to school as each placement breaks down; many PDA children end up being homeschooled when their anxiety levels are so high that they begin to refuse to attend school all together (Christie, 2007, p. 6). Students with PDA who are not supported in appropriate ways have been found to have much lower achievement overall than their cognitive abilities should dictate (Christie, 2007; Newson, 1989).

Newson and her research team discovered that PDA children did not respond to interventions in the same way that most children with autism responded, often with the typical interventions causing greater harm and leading to educational exclusion when the avoidance behaviours exhibited by students became too explosive for the school to handle (Newson, Le Maréchal, & David, 2003, p. 596). Green et al. (2018) echo this finding: “the best-intentioned responses of parents, teachers, or peers might inadvertently precipitate a further amplification of the individual’s distress and avoidant behaviour” (p. 458). These best-intentioned responses tend to include methods used to teach autistic students like those suggested by the BC Ministry of Education whose nearly 20-year old resource on teaching students with autism has no mention of PDA (BC Ministry of Education, Special Programs Branch, 2000). Newson, Le Maréchal, and David (2003) found that “the guidelines that are successful with autistic children need major adaptations for PDA children if any progress is to be made; these children hate routine and thrive best on novelty and variety” (p. 596). Yet if schools are not given the tools to work with PDA students in ways that are appropriate to their challenges, they will undoubtedly fall back on strategies that are recommended for students with autism. Unfortunately, professional development surrounding does not appear to be available to BC educators. A review of the course syllabi for professional development options available through the Provincial Outreach Program for Autism and Related Disorders (POPARD) (the province’s premier autism training

source for teachers) shows no mention of PDA (<http://www.autismoutreach.ca/training>).

Educators in BC are thus left with the unenviable task of trying to work with PDA students who exhibit challenging behaviours without the necessary training to appropriately respond to those behaviours.

Purpose

I first became interested in PDA after observing the experiences of a child who was diagnosed with Autism Spectrum Disorder (Level 1) using DSM-5 diagnostic standards. As part of the diagnostic process, the diagnosing psychologist provides a report to parents (who typically share the report with the child's school) that details a variety of recommended interventions to support the individual. The learning support team at this child's school tried many of these recommended interventions (which were typical of what is usually recommended for autism Level 1 support and not specific to PDA) yet with each intervention the child became increasingly disillusioned with school and eventually began to refuse to attend claiming that they no longer felt safe in the classroom environment. Despite following typical recommendations for autism interventions, this child's teachers were unable to provide this child with a safe and successful school experience.

British Columbia's *School Act* states that every child has the legal right to access an educational program within a public school district (Queen's Printer, 2018). Yet if a child does not feel safe in a school due to actions of the school staff (whether those actions are purposefully cruel or well-meaning but inappropriate due to a lack of knowledge) and the child consequently refuses to attend, their right to education is effectively being denied. The British Columbia Ministry of Education (2018) defines eight standards for teaching professionals called the "Standards for the Education, Competence and Professional Conduct of Educators in BC," the

first of which states: “Educators value and care for all students and act in their best interests” which includes a responsibility for the emotional and physical safety of students. If we as educators seek to follow the standards set out by the BC Ministry of Education (as is our professional duty), we have a responsibility to learn how to appropriately support students with PDA so that they can access the public education that is their right. When a school is knowledgeable about PDA and appropriate strategies, parents report higher satisfaction with school placements (Gore Langton & Frederickson, 2016, p. 261). As such, this paper will seek to answer the following research questions:

- How does PDA differ from typical ASD?
- Why are the differences between ASD and PDA significant to how students with PDA need to be supported?
- How does PDA affect the academic and interpersonal relationships of students?
- How does PDA affect the classroom environment?
- What types of strategies are most effective for students with PDA?
- How can we create safe, successful school experiences for students with PDA?

Definition of Terms

Special needs student. A student with special needs has “a disability of an intellectual, physical, sensory, emotional or behavioural nature, has a learning disability or has exceptional gifts or talents” (BC Ministry of Education, Governance and Legislation Branch, 2018b, p. E-73). School boards are legally bound to provide a student with special needs with an educational program (BC Ministry of Education, Governance and Legislation Branch, 2018b, p. E-73).

Inclusive education. British Columbia’s education system is based on inclusion where “students with special needs are fully participating members of a community of learners” (BC

Ministry of Education, 2016, p. 2). Inclusion does not always mean full integration within a typical classroom (although this is the goal for most special needs students). Rather, school boards are authorized to offer resource rooms, self-contained classes, community-based programs, or specialized settings when reasonable efforts at full integration have shown that a full-time program in a typical classroom does not meet the student's educational needs and/or the educational needs of other students in the classroom (BC Ministry of Education, 2016, p. 2-3).

Individual education plan. The BC Ministry of Education (2016) defines an Individual Education Plan (IEP) as “a documented plan developed for a student with special needs that describes individualized goals, adaptations, modifications, the services to be provided, and includes measures for tracking achievement” (p. V). Each student with a designation must have an IEP, and school staff are legally bound to offer learning activities in accordance with the IEP (BC Ministry of Education, Governance and Legislation Branch, 2018a, p. E-46). Parents, and the student themselves when appropriate, are invited to work together with school staff on the creation of the IEP (BC Ministry of Education, 2016, p. 3).

Adaptations and modifications. Adaptations are teaching and assessment strategies that are specific to a student's learning needs and allow the student to meet the learning outcomes of the course or subject that other students at that grade level would be expected to meet (BC Ministry of Education, 2016, p. V). For example, an adaptation for a student with slower processing speeds may be to allow more time to complete assignments or tests. In contrast, modifications are individual learning goals that are different from learning outcomes required by a course or subject where the student would not be expected to meet the same learning outcomes as other students at their grade level (BC Ministry of Education, 2016, p. VI). For example, a student in a modified program would not be expected to complete the same assignment as their

peers, but rather may be given a simplified version of the assignment that meets their individual learning goals but does not fulfill the course learning outcomes.

School-based team. A school-based team is a group of school personnel who problem-solve and assist classroom teachers in supporting students with special needs (BC Ministry of Education, 2016, p. VI). Typically, school-based teams include administration (principal/vice-principal/head teacher), resource teachers, school counsellors, school psychologists, speech language pathologists, and other professionals employed by the school district that work with students with special needs (Shields, 2018).

Case manager. A case manager is a member of the school-based team who has been appointed to “co-ordinate development, documentation and implementation of the student's IEP” (BC Ministry of Education, 2016, p. 18). The case manager is typically a resource teacher or a school counsellor, depending on the type of special needs designation assigned to the student.

Resource teacher. A resource teacher (sometimes called a Learning Assistance Teacher) is responsible for organizing, maintaining, and integrating services for students with special needs within the school, as well as providing a link to support services at the district level (BC Ministry of Education, 2016, p. 23). Resource teachers may also be called upon to work with the classroom teacher to support students without a special needs designation such as English language learners or students with mild learning difficulties (BC Ministry of Education, 2016, p. 23).

Special needs funding. Special needs in British Columbian schools are divided into “categories,” which are known colloquially in schools as “designations.” These designations qualify a school board to access supplemental funding for some students with special needs. To qualify for a designation and therefore possible funding, a student must have had appropriate

assessment and have an IEP in place (Government of BC, 2002). Special needs designations are divided into three levels, each of which receives different supplemental funding per student per year. Level 1 designations include Physically Dependent (A) and Deafblind (B) and receive an additional \$38,800 of supplemental funding (Government of BC, 2002; Resource Management and Executive Financial Office, 2018, p. 6). Level 2 designations include Moderate to Profound Intellectual Disability (C), Physical Disability or Chronic Health Impairment (D), Visual Impairment (E), Deaf or Hard of Hearing (F), and Autism Spectrum Disorder (G); Level 2 designations qualify for \$19,400 of supplemental funding (Government of BC, 2002; Resource Management and Executive Financial Office, 2018, p. 6). Level 3 designations include Intensive Behaviour Interventions or Serious Mental Illness (H) which qualifies for an additional \$9,800 in supplemental funding (Government of BC, 2002; Resource Management and Executive Financial Office, 2018, p. 6). There are also four other special needs designations that do not have access to supplemental funding but who still must have an IEP in place: Mild Intellectual Disability (K), Gifted (P), Learning Disability (Q), and Moderate Behaviour Support/Mental Illness (R) (Government of BC, 2002). Regardless of what extra funding may be received for a student with a designation, funds are not specifically attached to that student. Districts take all funds received for students and distribute them based on what they assess to be the specific educational needs of a particular student (Camley, 2016). For example, a child who requires Level 3 autism support may need more funding to provide that support than a child who requires Level 1 autism support, however both children are considered a “G” designation and give the district access to the same amount of funding per child.

Educational assistant. An educational assistant (EA) (also called a teaching assistant) is a person other than a teacher who assists with carrying out educational programs in the

classroom (BC Ministry of Education, 2016, p. 10). EAs can carry out a variety of roles to aid special needs students in reaching their IEP goals, including personal care, implementing behavioural programs, and informal assessment of learning outcomes; EAs are not responsible for formal assessment of learning outcomes (BCTF/CUPE, 2009). Teachers and EAs are expected to work together to support students with special needs.

Chapter Summary

In this chapter I discussed how the lack of knowledge in BC schools about Pathological Demand Avoidance syndrome translates into decreased educational success for students with PDA. I detailed my research questions surrounding how schools can create better outcomes for children with PDA and defined key terms that I will use during the literature review in chapter 2.

Chapter 2: Literature Review

Introduction

Pathological Demand Avoidance is a profile within the autism spectrum but requires different strategies than are typically recommended for autistic students. Due to lack of knowledge about PDA, schools are underprepared to work successfully with students who have PDA. This chapter will discuss the differences between PDA and ASD and why these are important. I will detail how PDA affects students and schools. The chapter will end with strategies for effectively supporting students with PDA.

The Difference Between PDA and ASD

Development of the ASD diagnosis. Autism Spectrum Disorder (ASD) has a long and complicated history. The term “autistic” was originally coined in 1911 by Eugen Bleuler, a Swiss psychiatrist, to describe the self-absorption of individuals with schizophrenia (Lyons & Fitzgerald, 2007; Asperger, 1991; Robison, 2017). In the 1930’s, there were several staff at the Vienna Hospital children’s clinic who were noticing patterns of behaviour in patients that did not fall under any of the official diagnostic criteria available at that time. Senior psychiatrist, Georg Frankl, observed a disconnect in some children between their facial expressions, body language, and speech in 1933, while a psychologist at the same clinic, Anni Weiss, noted psychopathy (hidden intelligence, fixations, and communication impairments) in a case study in 1935; however, neither used the term “autistic” (Robison, 2017, p. 869). In 1932, a young pediatrician named Hans Asperger was hired by this same clinic and likely would have worked closely with both Frankl and Weiss. Asperger was the first to use the term “autistic” in a 1938 lecture (calling it “autistic psychopathy”) to describe a child he had treated at the children’s clinic (Robison, 2017, p. 865).

Hans Asperger. In 1944, Asperger submitted his thesis to the University of Vienna (written in German) which has been translated to “‘autistic psychopathy’ in childhood” (Robison, 2017, p. 867). Asperger’s paper offered four case studies of children (the earliest of whom Frankl and Weiss would have been aware of) who shared unique traits including severe impairment in social integration, delayed motor milestones, stereotypic movements, minimal eye contact, unusual sensory interests, difficulties with reciprocity of social interactions, average to above average intelligence, special interests, and differences in processing speeds (Asperger, 1991).

Leo Kanner. Frankl emigrated to America in 1937 (to join with Weiss who had emigrated in 1934 and whom he married shortly after emigrating) and was hired by John Hopkins Harriet Lane Children’s Home to work with an Austrian-American psychiatrist named Leo Kanner (Robison, 2017, p. 865). Robison (2017) posits that Frankl shared his experiences from the Vienna Hospital children’s clinic with Kanner as they tried to form a diagnosis for a patient named Donald Triplett who showed similar traits to the child in Weiss’s 1935 case study (p. 865). Through his work with Donald Triplett, Kanner noted similar traits in other children. In 1943, Kanner published a paper entitled “Autistic disturbances of affective contact.” In this paper he noted a set of traits that eleven children he had examined had in common and which differed from schizophrenia in that they appeared to be present from birth (schizophrenia having been seen to develop in previously healthy adults). These traits included an inability to relate to people and situations in an “ordinary” way, “extreme autistic aloneness,” speech delays (in most but not all of the children), delay in reaching for parents, excellent rote memory, echolalia (parrot-like repetitions of heard words), literalness, over-reactivity to sensory input, repetition and obsessive desire for sameness, stronger relation to objects than people, good cognitive

potential, and essentially “normal” physical appearance (Kanner, 1943). Kanner called these traits “inborn autistic disturbances of affective contact.” Kanner and Asperger had seemingly independently described a similar set of traits less than a year apart. Robison (2017) suggests that Frankl was the link between these two papers, having worked with both Asperger in Vienna and Kanner in New York (p. 865).

DSM-III. While both Kanner and Asperger had described autism as a personality disorder distinct from schizophrenia, individuals who exhibited autistic traits were given a diagnosis of “childhood-onset schizophrenia” for nearly four more decades. In 1980, autism was officially recognized in the *Diagnostic and Statistical Manual of Mental Disorders, Third Edition* (DSM-III) when two categories called “infantile autism” and “childhood onset pervasive developmental disorder” were added under the umbrella term “pervasive developmental disorders” (Harris, 2016, p. 1390; Mazurek et al., 2017, p. 2783). Pervasive developmental disorders (PDD) were considered “a group of severe, early developmental disorders characterized by delays and distortions in the development of social skills, cognition, and communication” (Tsai & Ghaziuddin, 2014, p. 323). Diagnostic criteria for infantile autism therefore included “age of onset before 30 months, pervasive lack of responsiveness to other people, gross deficits in language development, peculiar speech patterns (e.g., echolalia), and bizarre responses to the environment (e.g., resistance to change, peculiar interest in or attachments to animate or inanimate objects)” (Mazurek et al., 2017, p. 2783-2784). Childhood onset PDD differed from infantile autism in that onset was between 30 months to 12 years, and not all diagnostic criteria for infantile autism needed to be met (Tsai & Ghaziuddin, 2014, p. 323). These criteria were created using Kanner’s work as Asperger’s work was not yet known in English literature on the topic (Tsai & Ghaziuddin, 2014, p. 323).

DSM-III-R. In 1987, the DSM was updated to DSM-III Revised. Infantile autism and childhood onset PDD were amalgamated to “autistic disorder” and “PDD not otherwise specified” (PDD-NOS) (Tsai & Ghaziuddin, 2014, p. 323). Diagnostic criteria for autistic disorder were changed to a triadic approach (that did not specify age of onset) with three areas of impairment including social relatedness, social communication, and ritualistic and repetitive behaviors (Alessandri & Schneider, 2018). PDD-NOS allowed for diagnosis when not all criteria for autistic disorder were met and allowed for recognition of the variations in behaviour seen in autistic individuals (Tsai & Ghaziuddin, 2014, p. 323).

DSM-IV. The DSM was next updated to DSM-IV in 1994. By this time, Asperger’s work had become well-known and diagnosticians were noticing several distinct disorders that could fall under the PDD-NOS category. The DSM-IV therefore added three new subcategories under PDD (while keeping autistic disorder and PDD-NOS) including Rett’s disorder, childhood disintegrative disorder, and Asperger’s disorder (Tsai & Ghaziuddin, 2014, p. 324). The criteria for autistic disorder continued to include three categories with minimal change from those in the DSM-III-R: qualitative impairments in social interaction, qualitative impairments in communication, and restricted, repetitive and stereotyped patterns of behaviour, interests and activities (Mazurek et al., 2017, p. 2787). Asperger’s disorder differed from autistic disorder in that only qualitative impairments in social interaction and restricted, repetitive and stereotyped patterns of behaviour, interests and activities need to be exhibited, without impairment in communication or language delays (Autistic Society, 2016).

DSM-5. In 2013 the DSM was once again updated to the DSM-5, the manual which is currently used for diagnosis in Canada. This update brought major changes to how autism is diagnosed. The American Psychiatric Association’s Work Group on Neurodevelopmental

Disorders had reviewed the DSM-IV PDDs and suggested that Asperger's disorder, childhood disintegrative disorder, PDD-NOS, and autistic disorder were all variations on the same disorder with symptoms on a continuum from mild to severe (Tsai & Ghaziuddin, 2014, p. 324). These four previous sub-categories were now called "Autism Spectrum Disorder" (ASD) which replaced PDD as a category (Tsai & Ghaziuddin, 2014, p. 324). ASD in the DSM-5 falls under the category of "Neurodevelopmental Disorders," which also includes intellectual disabilities, communication disorders, attention-deficit/hyperactivity disorder, specific learning disorder, and motor disorders (American Psychiatric Association, 2013). The diagnostic criteria for ASD were simplified into two categories which are present in early development but may not be noticeable until social demands exceed the abilities of the individual: (1) persistent deficits in social communication and social interaction across multiple contexts, and (2) restricted, repetitive patterns of behavior, interests, or activities (which can include sensory differences) (Autism Canada, 2018). The DSM-5 further allows for levels of diagnosis, depending on how much support the individual requires: Level 1 – requiring support, Level 2 – requiring substantial support, and Level 3 – requiring very substantial support (Autism Canada, 2018). The complete diagnostic criteria from the DSM-5 are specified in Appendix A. While Canadian diagnosticians use the DSM-5, other countries may also use the International Statistical Classification of Diseases and Related Health Problems 10th Revision (ICD-10) which still divides Autism Spectrum Disorder into categories similar to those found in the DSM-IV: childhood autism, atypical autism, and Asperger syndrome (World Health Organization, 2016).

ASD Diagnosis in British Columbia. In British Columbia, diagnosis of ASD is done through a qualified psychologist, child psychiatrist, or pediatrician who has trained specifically in the diagnosis of autism using current DSM standards (Dua, 2003, p. 14). Constantino and

Charman (2016) specify “three pillars of the diagnostic process: (1) ascertainment of current symptomatology sufficient to meet criteria A, B, and D; (2) acquisition of a developmental history consistent with an ASD (criterion C, provided by a primary caregiver of the child whenever possible); and (3) clinician confirmation” (p. 281). In British Columbia, these pillars translate to:

- consultation with professionals from other disciplines where appropriate to ascertain medical and developmental history (e.g., speech-language pathologist, paediatrician, occupational therapist),
- a diagnostic interview with parents/caregivers using the Autism Diagnostic Interview–Revised (ADI-R),
- a standardized observation of the individual’s social and communicative behaviour and play using the Autism Diagnostic Observation Schedule–Generic (ADOS-G).
- and completion of a variety of standardized norm-referenced instruments to assess the individual’s cognitive and adaptive functioning, such as the Wechsler Preschool and Primary Scale of Intelligence (WPPSI) and the Vineland Adaptive Behavior Scales (choice of instruments is dependent on the age of the individual) (Dua, 2003, p. 15-17).

A skilled diagnostician will compile the data from these varied pieces and determine whether an ASD diagnosis is appropriate, or whether the ASD-like symptoms can better be explained by an alternative psychiatric or developmental disorder.

Prevalence of ASD. The DSM-5 notes that reported frequencies for ASD in the United States and other countries is about 1% of the population (American Psychiatric Association, 2013, p. 55). The Public Health Agency of Canada (2018) recently put that estimate at 1 in 66

Canadian children and youth diagnosed with ASD, or about 1.5% of the population (p. 8). Approximately four times more males are diagnosed with ASD than females (American Psychiatric Association, 2013, p. 57; Public Health Agency of Canada, 2018, p. 9). British Columbia's numbers for diagnosis are slightly under the Canadian average, with 1 in 68 children and youth diagnosed, and a 1:5 ratio of males to females (Public Health Agency of Canada, 2018, p. 13). These numbers equate to 1.7% of British Columbian students having an ASD (G) designation (BC Ministry of Education, 2017). It is also important to note that many children and youth may have ASD but are not diagnosed due to barriers to diagnosis such as gender (with girls often being under-diagnosed due to how ASD may present differently in girls), maternal age (younger mothers may find it more difficult to identify problems), and the presence of maternal depression (Russell, Steer, & Golding, 2011). Other authors have found race and socio-economic status to impact the ability to achieve an autism diagnosis with non-whites and those with a lower socio-economic status having lower rates of diagnosis or later age of diagnosis (Broder-Fingert et al., 2018; Fountain, King, & Bearman, 2010; Zuckerman et al., 2014). As such, actual numbers of children and youth with ASD may be higher than what is gleaned from diagnostic data.

Development of a PDA diagnosis. The development of Pathological Demand Avoidance Syndrome is linked to the DSM-III-R's PDD-NOS diagnosis. In the 1980s, a British developmental psychologist named Elizabeth Newson identified a pattern of characteristics in children who had been referred to the Child Development Research Unit at Nottingham University for assessment for communication and developmental difficulties (Christie, Duncan, Fidler & Healy, 2012, p. 11). While these children fit some of the diagnostic criteria for autistic disorder, they did not fit enough of the criteria for a specific diagnosis and as such were typically

given a diagnosis of “pervasive developmental disorder not otherwise specified” (PDD-NOS). Newson felt this diagnosis was not a sufficient descriptor since it left parents in “the limbo of atypicality” rather than with a specific diagnosis that could allow better access to support for their child (Newson, Le Maréchal, & David, 2003, p. 595). Newson had posited that the demand avoidance prevalent in PDA was due to the child’s “failure to code social identity and consequent lack of social need to comply” (1989, p. 24) She therefore included PDA under a grouping she called “pervasive developmental coding disorders” which also included autism, dysphasia and dyslexia (see Appendix B).

From a distinct syndrome to part of the autism spectrum. As understanding of autism continued to deepen with the move from the DSM-III-R to DSM-IV (where Asperger’s was added as a diagnosable syndrome), Newson, Le Maréchal, and David (2003) re-conceptualized Newson’s original 1998 scheme to include PDA under the “family of pervasive developmental disorders” (which they noted could be called the “autism spectrum”) (see Appendix C). In this new conception, dysphasia and dyslexia were removed, however Newson, Le Maréchal, and David (2003) continued to see coding, or “making sense” of the world, as a feature that all syndromes under the family of PDDs had in common (p. 598). The central feature of this new syndrome was “an obsessional avoidance of the ordinary demands of life coupled with a degree of sociability that allowed social manipulation as a major skill” (Newson, Le Maréchal, & David, 2003, p. 596).

Even though Newson placed PDA under the umbrella of the autism spectrum, she still felt that PDA should be considered a distinctly diagnosable syndrome both to help parents feel that the diagnosis was accurate for their child, and also because she had found that PDA children needed different interventions than other autistic children (Newson, Le Maréchal, & David,

2003, p. 596). Wing, Gould, and Gillberg (2011) suggest that PDA may be a “double hit,” an additional problem in autism but not due to autism (p. 769). Unfortunately, the DSM-5 no longer distinguished between different types of autism, and PDA was left in relative obscurity. Christie (2007) argues that the debate over whether PDA is a distinct syndrome or a profile under the autism spectrum distracts from the “true purpose of diagnosis” which is to better understand individuals to “help us formulate more effective forms of intervention and provision” (p. 5). PDA is now considered a profile under the umbrella of ASD in the UK (National Autistic Society, 2017) but is not currently recognized as a diagnosis by itself (PDA Society, 2018). In Canada, PDA is absent from the Autism Canada website, and was not mentioned in the government’s most recent report on ASD (Public Health Agency of Canada, 2018).

Diagnostic criteria for PDA. Newson’s final conception of Pathological Demand Avoidance Syndrome was based on her observations of 150 children who shaped a list of eight behavioural features to define the PDA profile as:

1. Passive early history in the first year of life (e.g., did not reach for toys)
2. Resisting and avoiding ordinary demands of life using socially manipulative strategies
3. Surface sociability, but seems to lack a sense of identity, pride, or shame
4. Lability of mood, impulsivity, led by the need to control
5. Comfortable in role play and pretending
6. Language delay (perhaps as the result of passivity), but good catch-up often independent of speech therapy
7. Obsessional behaviour, often directed towards other people
8. Neurological involvement, such as being slow to achieve motor milestones, or exhibiting attentional difficulties (Newson, Le Maréchal, & David, 2003, p. 597).

Christie, Duncan, Fidler, and Healy (2012) suggest that passive early history, language delay, and neurological involvement should not be considered essential for diagnosis since those three features are not always present in children who otherwise fit the PDA profile. The UK's National Autistic Society (2017) agrees with this reduced list, noting the following six features as representative of the PDA profile:

- resists and avoids the ordinary demands of life
- uses social strategies as part of avoidance, e.g., distracting, giving excuses
- appears sociable, but lacks understanding
- experiences excessive mood swings and impulsivity
- appears comfortable in role play and pretence
- displays obsessive behaviour that is often focused on other people

How PDA is currently diagnosed. Since PDA is not a recognized disorder under the DSM-5, diagnosis can be difficult to achieve outside of the few diagnostic centres that specialize in PDA in the UK. Best practice suggests that a diagnostician should include the following as part of all autism assessments: “rigorous trait description, multidisciplinary assessment of the transaction between the child’s characteristics and their environment, and identification of co-occurring mental health disorders” to ascertain whether recognition of a demand avoidant profile is helpful when creating an intervention and management plan (Green et al, 2018, p. 455). This is typically what is included in an assessment in British Columbia (Dua, 2003, p. 15-17) however without knowledge of the existence of PDA as a possible profile, it is unknown whether diagnosticians in British Columbia are able to diagnose demand avoidance and suggest appropriate strategies.

Standardized measures for PDA. In the absence of a standardized test to assess for PDA, O’Nions, Christie, Gould, Viding, and Happé (2014) developed the Extreme Demand Avoidance Questionnaire (EDA-Q). The questionnaire (designed to be completed by parents) was tested with relative success, identifying individuals who had already been diagnosed with or suspected to have PDA, but not always distinguishing well between PDA and autism with disruptive behaviour. O’Nions et al. (2014) suggest that a “score on the EDA-Q might be viewed as an indicator of risk and a pointer towards possibly relevant PDA approaches, rather than a diagnostic measure” (p. 22).

O’Nions et al. continued their research into ways to assess for PDA through using a previously developed autism assessment tool: the Diagnostic Interview for Social and Communication Disorders (DISCO). In 2015, their published work revealed that the DISCO could be used to assess for traits specific to the PDA profile by focusing on those traits that were not as common within the broader autism spectrum. The traits found to be stronger in the PDA group than the non-PDA ASD group include apparently manipulative behaviour, difficulties with other people, harassment of others, fantasizing, lying, cheating, stealing and socially shocking behaviour, while those with PDA also had a number of traits in common with their ASD non-PDA peers (lack of co-operation, changes in mood, anxiety, blaming others and making embarrassing remarks in public) (O’Nions et al., 2015, p. 418). All but one of the individuals assessed who met the criteria for PDA also were diagnosable with ASD. This is significant as their work suggests that PDA is a profile within the autism spectrum, rather than a distinct syndrome as Newson originally suggested in 1989.

How PDA differs from typical autism. Newson and Le Maréchal (1998) provide a comparison of PDA and autism/Asperger's, detailing what they saw as the differences between the conditions. Those differences are summarized in the table below.

Table 1. *Criteria for PDA compared with autism/Asperger's criteria (Newson & Le Maréchal, 1998, p. 2-3)*

PDA	Autism/Asperger's
Passive early history in first year (child appears "normal" at first)	Differences in child are visible early in life
Resisting and avoiding ordinary demands of life using socially manipulative strategies	Can be reluctant but strategies for avoidance are rarely consciously used
Seems sociable on the surface, but lacks depth, has enough empathy to manipulate	Lacks social empathy
Mood switches quickly, impulsive, need to be in control, activities must be on child's terms	Thrive on rules, routine, and predictability, rarely impulsive
Comfortable in role play and pretending	Inflexibility, lack symbolic and imaginative play
Language delay but good catch-up, eye contact generally good, some social mimicry	Language delay or non-verbal, poor eye contact, little facial expressions or gesture
Obsessive behaviour, often social in focus or for demand avoidance	Obsessive behaviour, but not typically for demand avoidance or social manipulation
Neurological involvement: clumsiness, physical awkwardness, late or no crawling	Comparable in autism, except with crawling

There are two significant differences to note in this comparison. First, children with PDA have more understanding of social norms than typically autistic children and are comfortable in role play. As such, they are able to use those social norms and the ability to pretend to avoid demands. Gillberg, Gillberg, Thompson, Biskupsto, and Billstedt (2015) suggest that this ability to use socially manipulative behaviour to avoid demands is the main difference between PDA and autism (p. 980). O’Nions et al. (2018) suggest that the term “strategic behaviour” is more accurate than “socially manipulative” in that attempts to avoid demands are sometimes blunt and lack subtlety (p. 6). Second, children with PDA need to feel in control of activities, and when they lack control, their moods can switch quickly to behaviour that can sometimes be extreme. O’Nions et al. (2014) argue that the difference between PDA and autism is in the goal of behaviour: “difficult behaviour in ASD may be to achieve a concrete goal or avoid a specific activity, as opposed to persistent avoidance of any requests to maintain control” (p. 22). These two differences – the need for control which is met with strategic behaviour to avoid demands – are the central differences between typical autism and PDA (O’Nions et al, 2014).

PDA and other syndromes. Other authors have suggested that the demand avoidance seen in PDA is not limited to only one syndrome, such as Gillberg (2014) who noted demand avoidance in individuals with language disorders, ADHD, selective mutism, anorexia nervosa, and epilepsy (p. 769). Trundle, Craig, and Stringer (2017) note demand avoidance behaviour in individuals with anti-social personality disorder. Woods (2017) notes that the types of extreme behaviours exhibited to avoid demands can also be seen in oppositional defiance disorder. Gore Langton and Frederickson (2018) suggest that PDA may even be a “triple hit” of autism, conduct problems (often labelled as oppositional defiance disorder), and anxiety (p. 17). Yet O’Nions and Noens (2018) caution against seeing demand avoidant behaviour as “defiant” since this may

imply the avoidance is due to the child's willfulness and cause caregivers to respond reactively to ensure their authority is asserted (p. 389).

Prevalence of PDA. Since PDA is not currently being diagnosed separately from ASD, prevalence rates in Canada are not available. However, Gillberg, Gillberg, Thompson, Biskupsto, and Billstedt (2015) studied the incidence of PDA on the Faroe Islands (18 islands located between Iceland and Norway). All residents born between 1985 to 1994 had been screened twice for ASD, once in 2002, and then again in 2009. These screenings identified 67 individuals with ASD (corresponding to 0.94% of the population), 50 of whom participated in the PDA prevalence study. Gillberg et al. (2015) found that nine individuals of the 50 participants who had previously been diagnosed with ASD also met the criteria for PDA, putting the prevalence of PDA on the Faroe Islands at approximately 0.18% of the total population, with rates approximately equal between males and females. In Newson's (1996) original case studies rates of PDA in males and females were also close to equal; this is a distinct difference between PDA and ASD where four times the number of males than females are diagnosed with ASD (p. 2). If Gillberg et al.'s (2015) data were to be extrapolated to British Columbia, it is possible that the prevalence of PDA in BC could be as high as 0.3% of the population or approximately 1 in 300 students (accounting for BC having an overall prevalence rate of ASD of 1.7% in school-aged children compared to the Faroe Islands' rate of 0.94%). However, without a way to track the prevalence of PDA through official diagnosis, it is impossible to know accurate prevalence rates in British Columbia.

The Effects of PDA on Students and Schools

PDA child as a learner. Having a child with PDA in your classroom can often feel like you are "walking on eggshells" due to the need to navigate their unpredictable behaviour

(Christie, Duncan, Fidler, & Healy, 2012, p. 28). After working with a number of children who fit the PDA profile, Christie, Duncan, Fidler, and Healy (2012) suggest the following characteristics of a PDA child as a learner (with not all necessarily being present at all times depending on the child's mood or circumstances). This profile is important to keep in mind since PDA can impact all areas of a child's experiences in school, including their mental health, interpersonal relationships, academic success, and the other children in the classroom.

- need to be in control
- explosive behaviour
- 'slipping under the radar' (as they seek to avoid demands by being 'busy getting nothing done')
- threatening language
- very poor sense of self-esteem
- expressed desire to be equal or better than
- desiring friendships but inadvertently sabotaging them
- ambivalence about success and enjoyment
- lack of permanence and transfer of learning and experience
- very poor emotional regulation
- variability in behaviour
- extensive involvement in fantasy and role play (p. 35-37)

The effect of PDA on mental health. Depression and anxiety are common among children and youth with ASD with possibly up to double the rates seen among their typically developing peers (DeFilippis, 2018). These rates increase among ASD individuals who have a higher IQ (Hurtig et al., 2009). White and Roberson-Nay (2009) suggest that "higher functioning

[ASD] youth who have an awareness of their social disability may experience anxiety related to misinterpreting social cues and expectations for social failure” (p. 1006) DeFilippis (2018) also notes that youth with ASD are more at risk for developing adverse reactions to anti-depressant medications (commonly used to treat anxiety and depression). Ghaziuddin (2002) found that anxiety-related concerns were the most common clinically-presenting problems in children and youth with ASD.

Being on the autism spectrum, children and youth with PDA could be expected to experience anxiety at rates like those found by DeFilippis (2018), however O’Nions et al. (2014) found that individuals with PDA actually exhibited more emotional symptoms such as anxiety and internalizing than others with autism (p. 541). Ogundele (2018) similarly states that “children with PDA exhibit higher levels of emotional symptoms compared to those with ASD” (p. 9). PDA is thought to originate from high levels of anxiety which lead to the need to maintain control and avoid other people’s demands (Fidler & Christie, 2019, p. 11). If anxiety is untreated, it can lead to depression, self-harm, substance abuse, and even suicide (Craske & Stein, 2016, p. 3051). Anxiety is also correlated with an increase in school refusal (Brandibas, Jeunier, Clanet & Fourasté, 2004).

The effect of PDA on interpersonal relationships. Deficits in social communication and interaction are a hallmark of an ASD diagnosis. The presence of anxiety exacerbates the social loneliness often experienced by youth with ASD (White & Roberson-Nay, 2009, p. 1011). Individuals with the PDA profile may appear more sociable on the surface, but O’Nions et al. (2015) found that individuals with PDA have substantially more socially shocking behaviour, inappropriate sociability, and difficulties with other people than their ASD peers. The behaviour of PDA children may seem unpredictable, domineering, and controlling leading to poor peer

interactions (O’Nions et al., 2014; O’Nions et al., 2018). Social loneliness is associated with decreased mental well-being, including depression, anxiety, and suicidal ideation (Lasgaard, Nielsen, Eriksen, & Goossens, 2010, p. 219).

The effect of PDA on academic success. The DSM-5 notes that individuals with ASD may experience issues with adaptive skills: “Extreme difficulties in planning, organization, and coping with change negatively impact academic achievement, even for students with above-average intelligence” (American Psychiatric Association, 2013, p. 57). PDA children may experience similar challenges, however their demand avoidance will cause them to function below their potential much of the time (Christie, 2007, p. 5-6). Christie, Duncan, Fidler, and Healy (2012) have observed that PDA children often experience sudden setbacks after prolonged periods of seemingly settled behaviour and progress (p. 38). The extreme behaviours typically present in children with PDA often lead to school exclusion, thus further impacting their ability to find academic success (Gore Langton & Frederickson, 2016, p. 260). Newson (1989) notes that most children with PDA will not achieve the academic success that their cognitive abilities would suggest possible, however children with higher intelligence tend to be more successful overall.

The effect of PDA on classroom environments. Children with PDA exhibit poor emotional regulation and variable, often explosive behaviour. While there are no studies on the impact of PDA behaviours on other children in the classroom, studies do exist about aggressive behaviour in the classroom. Powers and Bierman (2013) note that aggressive behaviour from one student can increase aggression in the early elementary classroom overall, and that this increase is more prevalent in students who are disliked by their peers. This study suggests that the

presence of an explosive, aggressive PDA child may cause other vulnerable children in the classroom to exhibit similar, aggressive behaviours, particularly in early elementary classrooms.

Supporting Students with PDA

Autism support in BC schools. Students in British Columbian public schools with a diagnosis of autism spectrum disorder are eligible for a category G designation and special needs funding supplement of \$19,400 per year (Government of BC, 2002; Resource Management and Executive Financial Office, 2018, p. 6). The funding supplement is meant to provide access to supports like educational assistants and time with a resource teacher, as the school administrator deems is necessary for the student to be successful in the classroom (BC Ministry of Education, 2016, p. 9). The special needs designation gives autistic students access to an Individual Education Plan (IEP) (developed by the case manager in consultation with parents/guardians) which includes descriptions of any adaptations or modifications that need to be made, as well as supports that are required for the student (BC Ministry of Education, 2016, p. V). An IEP must be reviewed at least once each school year to ensure that it is still accurate to the student's needs (BC Ministry of Education, 2016, p. 3). The IEP is a legal document that must be followed by school staff; if supports described in the IEP are not available at the school level, they must be provided by the district or available in the community (BC Ministry of Education, 2016, p. 3).

IEP goals for autistic students should focus on:

- “socially adaptive behaviours and social responsiveness;
- motor development;
- communicative competence;
- and academic performance” (BC Ministry of Education, 2016, p. 88).

The role of the resource teacher. The resource teacher is “a member of the school-based team, provides collaborative consultation, assists with pre-referral interventions and works closely with teachers and the school-based team to plan for, organize and access support services for students with special needs” (BC Ministry of Education, 2016, p. 23). Resource teachers must have university-level training in working with students with special needs and strategies to adapt and modify curriculum (BC Ministry of Education, 2016, p. 25). Resource teachers use this knowledge to advise classroom teachers on adjustments to curriculum or instruction methods, or in altering the classroom environment to better facilitate learning for a student or a group of students (BC Ministry of Education, 2016, p. 24). Resource teachers who work with autistic students should have specific training in “behaviour management and skill development in social interaction, verbal and non-verbal communication, and social skills” (BC Ministry of Education, 2016, p. 89).

The role of the school counsellor. The school counsellor is a member of the school-based team and may assist with implementing social skills and life skills programs for students with special needs, including those with autism (BC Ministry of Education, 2016, p. 27). School counsellors may also work with classroom teachers to help ameliorate issues that may precipitate problems for a student (BC Ministry of Education, 2016, p. 27). For example, a school counsellor may advise a classroom teacher on strategies to reduce the impact of situations that provoke anxiety in an autistic student (BC Ministry of Education, Special Programs Branch, 2000, p. 19).

The role of the classroom teacher. The classroom teacher is responsible for designing, supervising, and assessing the educational program for a student with an IEP (BC Ministry of Education, 2016, p. 9). This may be done in consultation with a resource teacher when

specialized instruction is required (BC Ministry of Education, 2016, p. 9). Classroom teachers are not expected to have specialized training in working with students with special needs.

The role of the educational assistant. Educational assistant work with the classroom teacher to support students with special needs and to implement the program specified in the IEP (BC Ministry of Education, 2016, p. 10). Educational assistants who work with autistic students should have specific training in:

- “observing and gathering data about behaviour;
- shaping appropriate behaviour using behavioural techniques;
- stimulating communication;
- developing skills for independent living; and
- facilitating peer interaction and relationships” (BC Ministry of Education, 2016, p. 89).

Inservice training should be provided for educational assistants to further develop their expertise in these areas (BC Ministry of Education, 2016, p. 26).

The role of the Provincial Outreach Program for Autism and Related Disorders (POPARD). POPARD’s role is to “provide consultation, training and support services to all public and independent schools across the province of British Columbia with a primary focus on increasing the capacity of school district staff to support students with autism spectrum disorder (ASD)” (Provincial Outreach Program for Autism and Related Disorders, n.d.). POPARD can work with school staff to create educational and behavioural programs, provide consultation on how to better support a specific autistic student, or provide training to school staff about autism and school-based interventions (BC Ministry of Education, Special Programs Branch, 2000, p.

24). POPARD's services are based on a specific intervention for autism called applied behaviour analysis (ABA).

Applied behaviour analysis (ABA). ABA was inspired by B.F. Skinner's work on operant conditioning which posited that behaviour could be analyzed by considering antecedents, the behaviour itself, and the consequences that follow the behaviour (Morgan, 2018, p. 101). These are now known as the ABCs of behaviour (antecedent, behaviour, consequence) (BC Ministry of Education, Special Programs Branch, 2000, p. 113). In the 1960's and 70's, a behavioural psychologist named O. Ivar Lovaas applied Skinner's principles to the treatment of autistic children who were non-verbal and showed that ABA principles could be used to teach these children to speak (Smith & Eikeseth, 2011, p. 376). In 1987, Lovaas published a report that showed that autistic children who received early intensive ABA had vastly better outcomes than autistic children who received little to no ABA (Smith & Eikeseth, 2011, p. 377). This report had a significant impact on the treatment of autistic children and ABA has now become synonymous with ASD interventions (Trump et al., 2018, p. 382). It can be defined as an approach that "involves direct observation and recording of relevant target behaviors, systematic and continuous data collection, and implementation of interventions designed to address behavioral deficiencies or excesses" (Morgan, 2018, p. 100). ABA is the approach recommended by the BC Ministry of Education for teaching autistic children (BC Ministry of Education, Special Programs Branch, 2000, p. 129).

Criticism of ABA. In the past, ABA has been criticized for its use of harsh punishments to change behaviour, however modern-day ABA tends to focus more on positive reinforcement for preferred behaviours rather than punishment of unwanted behaviours (Trump et al., 2018, p. 383-384). ABA has also been criticized for its focus on compliance since the criterion for

demonstrating compliance is often set by someone other than the autistic individual (such as a teacher or educational assistant) which can lead the child to become vulnerable to harm and abuse since their understanding of consent may be impacted by repeated rewards for compliance (Trump et al., 2018, p. 384). ABA has also been criticized for its use of reward systems to reinforce behaviour, rewards being seen by some as “bribes” since positive reinforcement and bribery are easily confused (Trump et al., 2018, p. 385). Lastly, the most prominent critics of ABA are autistic adults who have been shown to have high incidences of post-traumatic stress disorder after having been through ABA interventions in childhood (Kupferstein, 2018, p. 26).

ABA approaches to supporting autistic children in schools. Despite these criticisms of ABA, it continues to be the most commonly used approach to autism intervention in schools. When dealing with challenging behaviour from autistic children, the BC Ministry of Education recommends the use of a behaviour intervention plan that evaluates the ABCs of behaviour and includes identification of alternative behaviour and strategies for changing the challenging behaviour (BC Ministry of Education, Special Programs Branch, 2000, p. 57). These strategies may include environmental adaptations to adjust the classroom to better support the preferred alternative behaviour, using positive program strategies (detailed below), reactive or consequence-based interventions (e.g., ignoring the behaviour, redirection, or removal of reinforcements to the undesirable behaviour), or the development of a token system to reward preferred behaviours (but not removing tokens as punishment) (BC Ministry of Education, Special Programs Branch, 2000, p. 61-68).

Positive program strategies. The BC Ministry of Education recommends a variety of strategies to promote development of communication and positive behaviours in autistic students, including:

- Using visual aids such as visual daily schedules, pictorial instructions for tasks, and pictures of appropriate behaviour
- Providing precise, positive praise
- Using reinforcement to increase preferred behaviours, such as praise, tangible objects, or preferred activities
- Provide opportunities for choice within limited options so as to not overwhelm the child with too many choices
- Pay attention to processing and pacing by breaking down oral instructions into smaller steps and providing visual cues
- Break down large tasks into multiple, small, teachable steps
- Use discrete trial strategies to increase positive behaviours (e.g., the instructor gives a command, prompts the student to follow it, the student responds by either following the instruction or not, behaviour is rewarded if positive or ignored if not what the instructor wanted to see)
- Use the student's interests and fixations to teach concepts and provide opportunities to develop further expertise in that area
- Provide a structured, predictable classroom environment
- Observe sensory responses and adapt the environment to prevent anxiety responses before they occur
- Provide an area for relaxation and calming
- Provide opportunities for interaction with peers who show appropriate social behaviour
- Use clear, concise language

- Use individualized social stories (a description of a social situation that includes social cues and appropriate responses) to teach social skills
- Use direct instruction to teach specific social rules such as waiting, taking turns, how to handle transitions, changing the topic in a conversation, finishing, initiating, being flexible, and being quiet
- Use social skills training groups
- Teach functional skills such as self care, functional academics, vocational skills, leisure skills, and community skills (BC Ministry of Education, Special Programs Branch, 2000, p. 27-56).

Positive behaviour support (PBS). PBS is increasingly being used by schools to deal with disruptive behaviours, including those found in autistic students (Kern Koegel, 2018). PBS uses the principles of ABA but is said to take a more person-centred approach (Ogundele, 2018, p. 15). Kincaid et al. (2016) provide the following definition of PBS: “PBS is an approach to behavior support that includes an ongoing process of research-based assessment, intervention, and data-based decision making focused on building social and other functional competencies, creating supportive contexts, and preventing the occurrence of problem behaviors. PBS relies on strategies that are respectful of a person’s dignity and overall well-being” (p. 71). PBS begins with a functional behaviour assessment (FBA) to identify the function of the behaviour and why it is occurring using the framework of the ABCs of behaviour (Kern Koegel, 2018). Antecedent interventions are used to prevent disruptive behaviours, rewards are used to increase preferred/alternative behaviours, and consequences are used to decrease disruptive behaviours (Kern Koegel, 2018). PBS is meant to be a kinder approach than ABA in that it does not include the use of aversive punishment-based consequences (Kincaid et al., 2016). However, Brown,

Michaels, Oliva, and Woolf (2008) found that some PBS practitioners would use these intrusive consequences if they felt they were warranted, and that many ABA practitioners have stopped using punishment-based consequences as these have become less socially acceptable. Thus, it could be said that PBS is just ABA with a new name.

Why support for PDA differs from typical autism. Christie (2007) suggests that for all children, not just those with PDA, the task is to “match the curriculum, approach and support that is required to the child’s individual needs” (p. 5). PDA is rooted in anxiety which results in demand avoidance to maintain control of situations and alleviate the feelings of anxiety caused by being out of control. With the focus on compliance, many ABA strategies used in schools take that control away from the child. In particular, the use of reward/consequence models are problematic for children with PDA. O’Nions and Noens (2018) suggest that rewards to increase preferred behaviours do not help the child to regulate their distress associated with the aversive demand and that the inability to regulate that distress to achieve the reward may result in increased frustration (p. 389). Punishment-based approaches like time-outs can also increase distress since the child is blocked from physically escaping the demand context (O’Nions & Noens, 2018, p. 389). Instead, the anxiety that is at the root of the demand avoidance needs to be addressed, and the child needs to be provided with functional responses to the demand rather than just rewards or consequences (O’Nions & Noens, 2018, p. 389). O’Nions, Happé, Viding, Gould, and Noens (2018) suggest that inappropriate management of avoidance behaviours can lead to escalation of these behaviours in response to demands (p. e14). This is the opposite of what ABA or PBS techniques are seeking to achieve. Thus, the use of “structure, routine and behavioural principles of reward that are usually effective for children with autism or Asperger’s syndrome are rarely so for children with PDA” (Christie, 2007, p.6).

Strategies to support PDA students. Some of the supports suggested by the BC Ministry of Education for students with autism will also work for students with a PDA profile, including using visual aids, providing extra processing time, personalizing the curriculum, and using routines for predictability (Fidler & Christie, 2019, p. 40). However, the core principle for any strategy used with PDA children is collaboration: “working with the child or young person, finding a way to negotiate solutions, adjusting expectations, compromising on outcomes and collaborating closely with parents and others” (Fidler & Christie, 2019, p. 31). It is important to note that collaboration is not a one-way process where the teacher imparts compliance, but rather every interaction with a child with PDA can be considered transactional; adults must not only look at the child’s behaviour, but also at their own contribution to the situation that caused the behaviour (Christie, Duncan, Fidler & Healy, 2012, p. 44). Consequently, the key qualities that a school should seek to fulfil to create the right environment to support a child with PDA are: “tolerance, imagination, determination to succeed, adaptability, positive interest in working with an unusual and challenging child, and a commitment to integration” (Newson, 2016, p. 3). A variety of specific strategies have been found to be helpful in working with PDA children, as detailed below.

Keyworker. Newson (2016) suggests that schools take a “keyworker” approach where one person is designated to build a solid relationship with the PDA child since relationships have been found to be more useful than consistency in making progress (p. 4). The keyworker should be highly flexible, imaginative, a good negotiator, have patience, a good sense of humour, and enjoy a challenge (Newson, 2016, p. 4). Fidler and Christie (2019) also note that adults working with PDA children should understand why a child is acting the way they are to have the right mindset: “If we understand and hold the view that the pupil’s avoidance is an anxiety-driven

need to be in control and avoid other people's demands and expectations we realise...that they can't help the fact that they won't do it on this occasion" (p. 25). Adults who have this mindset will typically find better success in working with a PDA child since they will not engage in power struggles.

Prioritize expectations. PDA children do need basic ground rules that they are expected to follow, however these expectations should be kept to a minimum since demands are triggering for PDA students (PDA Society UK, 2016, p. 25). Fidler and Christie (2019) suggest sorting expectations into levels of priority: high priority expectations are non-negotiable, while medium and low priority expectations can be flexible (p. 44). Examples of high priority ground rules may include those related to safety, class participation, or to the child's enjoyment of school (Fidler & Christie, 2019, p. 41). High priority expectations should be kept to a minimum to encourage student buy-in. Fidler and Christie (2019) suggest the use of a Priority Rating Chart that includes a rationale for the expectation and a plan for adults to use in supporting the child to reach the expectation (an example is included in Appendix D). The PDA Society UK (2016) suggests techniques like "passing over responsibility" (e.g., 'I'm sorry, I didn't make this rule, it's a health and safety requirement') or giving choices within expectations to allow the child to feel autonomous (p. 25).

Adjusting demands according to level of tolerance. While it is important to prioritize expectations and demands, it is also important that adults monitor the child's tolerance for demands at any given moment which is dictated by the student's level of anxiety (Christie, Duncan, Fidler, & Healy, 2012, p. 51). When anxiety is high, the threshold for tolerating demands may be lower, and as such, the flexibility in medium and low priorities becomes necessary to ensure that the child's anxiety levels are not pushed even higher. When the child's

demand tolerance, or *threshold*, is high, expectations may be raised and demands increased, while when their threshold is low, pressure on the child needs to be reduced to allow the child's anxiety levels to return to a lower level (Christie, Duncan, Fidler, & Healy, 2012, p. 51). Adults working with PDA children must therefore not only be flexible, but also observant of the child's moods so that they can gauge the child's current threshold for demand tolerance before attempting to institute a demand.

Offering choices. PDA children need to feel in control; giving choices is one way to help them achieve this feeling. Newson (2016) suggests the strategy of offering a choice of two activities where the one that you really want the child to choose is the easier of the two (p. 4). Newson (2016) also cautions against using negativism (that is, using their avoidant nature to manipulate them to choose what you actually want them to do, such as making something seem harder than it is so they will choose the one that in truth is more difficult), since this may work at first, but sends the message that you are not trustworthy (p. 4). Fidler and Christie (2019) call this an "invitational approach," where you are giving the child an encouraging choice of joining in, rather than directing them to do so (p. 45). For example, if the goal is to get a child to complete a worksheet, the adult could ask, "Do you want to use crayons or felt tips to do this worksheet?" (Fidler & Christie, 2019, p. 45). Invitational approaches work best when they are said conversationally since the request feels more gently and is less likely to provoke demand anxiety (Fidler & Christie, 2019, p. 46).

Indirect/declarative language. Much of working with a PDA child relies on the adult's ability to be mindful of their use of language to reduce anxiety. In addition to invitational approaches, the use of indirect or declarative language is another method to consider. The idea behind declarative language is to "*declare* what you observe, what you are experiencing, or what

you see your child doing” (Wade, n.d., p. 1). Declarative language is useful for all children with ASD since it “invites experience sharing, and provides an ideal social framework for later conversational interactions” (Murphy, 2010, p. 9). Declarative language contrasts with imperative language where the adult is questioning or commanding the child (Murphy, 2010, p. 8).

Thinking out loud. One way to use declarative language is to think out loud, which Carlile (2009) suggests is “one of the most effective strategies to reduce anxiety and to enable the child to comply” (p. 53). Thinking out loud can include asking rhetorical questions (e.g., “I wonder what would happen if...”), sharing your inner narrative (e.g., “now when did I last see my keys?”), or making observations about what is happening in the environment (e.g., “I notice that all the kids are at the table”) (Fidler & Christie, 2019, p. 46; Murphy, 2010, p. 9-10). Rather than commanding a PDA child to do a task, thinking out loud allows the child to take the lead and decide how they would like to engage with a task, as well as provides a model for the child on problem solving skills (Fidler & Christie, 2019, p. 47-48).

Indirect praise. When working with children, we often give praise for tasks that are completed well to encourage the child and let them know that we are pleased. However, for a PDA child, “praise can be perceived as a signal of their compliance and of giving up of control” (Carlile, 2009, p. 53). PDA children want to be able to comply, but their anxiety often gets in the way of this. Using indirect praise therefore tells the child that they have done well, without implying that their performance was a sign of compliance (Carlile, 2009, p. 53). An example of indirect praise is, “wow, how did you manage to finish that assignment so quickly?” rather than the more direct praise of, “great job on finishing that assignment!” Reward charts, intended as an overt form of praise for a completed task, carry the implicit demand that the child must do the

task to get the reward; the demanding nature of reward charts are therefore not often successful with PDA children (Fidler & Christie, 2019, p. 68).

Complex language. The BC Ministry of Education suggests using clear and concise language with autistic students (BC Ministry of Education, Special Programs Branch, 2000, p. 40). In contrast, for children with PDA, more complex language may be advised: “Concise language can come across to the child with PDA as confrontational, while more complex language tends to feel more negotiative and may also intrigue the child” (PDA Society UK, 2016, p. 26). Fidler and Christie (2019) suggest complex language provides a more indirect approach to requests since it feels more conversational and less directive (p. 51). An example of a complex language approach to asking a child to get ready to clean up and go to an assembly is: “I can see the others are starting to clear up. It must be nearly time for assembly. I can help you tidy up if you like. Do you want to put your drawing pens away in your tray or are you going to leave them on your desk?... By the way did you notice that bird’s nest that Mrs. Norris found? It’s on the table outside the hall. We can look at it on the way to assembly. I was thinking of putting this chocolate egg in to give her a surprise! What do you reckon?” (Fidler & Christie, 2019, p. 51). This is a much different use of language than is typically used with ASD children where clear, concise commands are given to ensure the child has understood the requirement.

Humour. Humour is another useful way to use language to encourage the child to meet demands without provoking anxiety. The PDA Society UK (2016) suggest that humour can be used to “coax and cajole the child” (p. 26). Children with PDA may make unreasonable requests to test whether they are truly in control. Carlile (2009) suggests that using humour can diffuse the situation and calm the child, rather than just saying “no” to an unreasonable demand (p. 53). Adults can also make deliberate errors so that the PDA child can correct them with the adult’s

response being self-deprecating humour (Fidler & Christie, 2019, p. 47). This is why the keyworker needs a good sense of humour to work successfully with a PDA child (Newson, 2016, p. 4).

Novelty and variety. While most autistic children thrive on predictability and routine, PDA children may learn to exploit a predictable routine to avoid demands (PDA Society UK, 2016, p. 25). Fidler and Christie (2019) suggest that while a certain amount of predictability is important for reducing anxiety, too much can feel confining (p. 60). Novelty, variety, mystery, and suspense can be useful in helping hook a PDA child into a new activity or to manage the anxiety that comes along with an unplanned activity or change (PDA Society UK, 2016, p. 25).

Visual aids. Like many autistic children, visual aids are useful to children with PDA, however the approach to the use of visual aids is once again different. Visual aids for PDA children should avoid being prescriptive like a to-do list, and instead remain flexible and indirect (Fidler & Christie, 2019, p. 53). For example, rather than a visual schedule with specific tasks to be completed for each part of the day in a checklist format, a visual schedule for a PDA child would instead offer choices within a subject area, possibly created in consultation with the child (Fidler & Christie, 2019, p. 53-54). The PDA Society UK (2016) also suggests visual aids can be used to depersonalize demands (e.g., “what does the schedule say we do next?”) (p. 25).

Preventing meltdowns. Meltdowns are common among children with ASD and are different than tantrums; tantrums are goal-oriented whereas meltdowns are a response to being overwhelmed (Fidler & Christie, 2019, p. 64). Meltdowns can be explosive and consequently present danger to other children in the classroom, or the child may simply shutdown and become unresponsive (Fidler & Christie, 2019, p. 64). Since meltdowns in PDA children may last for hours and are exhausting for everyone involved, a major goal of working with a PDA child

should be to avoid exacerbating the child's anxiety to the level where a meltdown will happen (Christie, Duncan, Fidler, & Healy, 2012, p. 82). All of the strategies detailed above will help to keep a PDA child's anxiety to a level where meltdowns can be avoided. In addition, other strategies to use when a child is beginning to become heightened include avoiding unnecessary confrontation, using distraction to alter the mood and guide the child back to preferred behaviour, planned ignoring when the child does something just to be provocative, legitimizing behaviours (e.g., if the child continually leaves the classroom, give them a legitimate reason to leave the classroom like taking a note to the office), and adjusting expectations to a level that is closer to the child's current tolerance level (Fidler & Christie, 2019, p. 61-63). The PDA Society UK (2016) also suggests using strategies to reduce overall anxiety like teaching relaxation techniques, increasing physical exercise, and providing a safe space within the school as a physical and psychological refuge (p. 26).

Managing meltdowns. Even with the best and most patient approaches, it is likely the PDA child will still experience meltdowns. Much like a panic attack, a child in meltdown does not have control over their behaviour (Christie, Duncan, Fidler, & Healy, 2012, p. 83). Adults should use the following techniques to get through a meltdown: staying calm (remember body language and tone of voice), assess the risks and think about the options available, communicate with other adults for a coordinated response, and use appropriate interventions if safety is challenged (that have been agreed upon with parents and staff prior to the incident as part of crisis planning) (Fidler & Christie, 2019, p. 44). The use of a safe space for the child to recover is also important to give them a private place to compose themselves, as well as giving staff time to regroup (PDA Society UK, 2016, p. 25). After a meltdown, repairing the relationships that may have sustained damage (between the child, support adults, and other children) in the

classroom should be a priority since positive relationships are so important to PDA children (Fidler & Christie, 2019, p. 66). It is also important to note that PDA children do not respond well to sanctions, and that punishments for meltdowns are inappropriate (Fidler & Christie, 2019, p. 67).

Social support. PDA children will often struggle with peer interactions. Newson (2016) suggests a program called “Circle of Friends” as part of the personal and social education curriculum for the whole classroom (p. 3). The Circle of Friends program is described as “a social and language skills program of inclusion that provides valuable support to students with special needs. It is based on the establishment of friendships between students with disabilities and their trained, non-disabled peers as both interact meaningfully in the natural environment” (Circle of Friends – The Path to Inclusion, 2016). An overview of the Circle of Friends program is provided in Appendix E. Calabrese et al. (2008) found that Circle of Friends makes a profound contribution to the quality of life of everyone involved, including the student with the disability, their parents, their peers, and the sponsors of the program.

Inclusive education. The focus on inclusion in the Circle of Friends program echoes what parents of children with PDA have identified as essential to a positive school placement: “a successful placement is one in which their child is *included* in the broadest sense” (Gore Langton & Frederickson, 2016, p. 261). It is important to note that inclusion of children with special needs is different than integration: “True inclusion only happens when a whole school embraces diversity and creates an environment where everyone belongs” (Kulusic et al., 2014, p. 6). Inclusion has been shown to not only benefit the child with special needs, but other children in the classroom as well (Kulusic et al., 2014, p. 6). Through a focus on inclusion, all children in

the classroom will be supported to reach their full potential, including children with pathological demand avoidance.

Chapter Summary

This chapter began with a discussion of how the PDA profile was developed by Elizabeth Newson in the 1980s. The differences between typical autism and the PDA profile were explored, as well as how PDA can affect learning, mental health, interpersonal relationships, and the classroom environment. Lastly, strategies that are effective for children with typical autism were contrasted to those that are effective for children with PDA. In the next chapter, I will discuss how this information can be used to create a professional development workshop for schools on one of these strategies: declarative language.

Chapter 3: Summary, Recommendations and Conclusions

Summary

Working with students who exhibit the PDA profile is challenging in that many of the strategies that seem to work with most autistic children end up creating the opposite effect in PDA children. While PDA is increasingly gaining acceptance as a profile under the autism spectrum, it is little known in Canada and as such, schools that encounter PDA children may not know how to best support them. In Chapter 2, I described a wide array of strategies that have been found to be successful when working with PDA children. This final chapter will detail my recommendations of how schools can use one of these strategies – declarative language – to better support children with PDA.

Recommendations

The BC Ministry of Education (2016) recommends the creation of an “ongoing staff development plan” to “ensure that all personnel who work with students with special needs have access to relevant in-service training opportunities in order to foster evidence-informed practice” (p. 6). PDA is not well-known within our school system, and as such, most teachers and support staff will have little knowledge of how best to work with these potentially challenging children. PDA children may be found in all types of classrooms, from mainstream to specialized. As such, I recommend the creation of a professional development workshop for all school staff at all grade levels that teaches one specific strategy that will be helpful for not only PDA children, but all children. The strategy I recommend this workshop to focus on is declarative language.

Imperative vs declarative language. Imperative language is a quick and easy way to tell a child to do something, however, it does little to encourage intrinsic motivation and provides the perfect conditions for struggles over control (Wade, n.d., p. 1). We hear imperative language

every day in our classrooms as the adults in charge tell students to sit down, stop talking, work on this assignment, go out for recess, etc. Imperative language is directive and many adults are comfortable in this commanding role since it was what they experienced in their own schooling. In contrast, declarative language invites empathy, validates the child's perspective, builds body and environmental awareness, helps build problem solving skills, and builds the capacity of both children and adults to better describe emotions (Wade, n.d., p. 1-2). Declarative language is a kinder way to talk to people in general and can be used with all students to encourage relationship-building through shared experiences (Murphy, 2010, p. 8). For example, an imperative language statement like "go sit down in that chair" simply gets a student to do the task, however if that statement is changed to be more declarative ("I wonder where we should sit?") the power is put with the student to decide on their seating location, and also allows the teacher to observe the location the student prefers for their seat. While both methods get a student to sit down, there is far more information to be observed from declarative language than imperative, and less opportunity for the student to say "no" which can result in a power struggle. Declarative language takes time to learn and may not be intuitive, however I believe using declarative language with all students, not just those with PDA, will lead to kinder, more empathic classrooms overall.

Professional development workshop on declarative language. I have often heard fellow teachers remark that the most valuable professional development workshops they have attended are those in which they are given a specific strategy that can be used in their classroom the next day. This goal of this 3-hour long workshop, therefore, would be to frame declarative language as a strategy that can be used immediately, and to provide the opportunity to practice the skill to begin to work towards mastery. The general topics covered would include:

- What is imperative language?
- What is declarative language?
- How do declarative language and imperative language differ?
- Why should we use declarative language? Who benefits?
- What does declarative language sound like?

The workshop would conclude with practicing declarative language in small groups, and a challenge to begin using declarative language in everyday practice. A more detailed outline of this workshop is available in Appendix F.

Recommendations for Future Research

This workshop could inspire a wide variety of research questions for future study, including:

- Is this workshop effective at increasing teachers' knowledge of declarative language? (study design could include a pre and post-workshop survey for teachers on knowledge of declarative language)
- Is this workshop effective at increasing teachers' use of declarative language? (study design could include both a pre and post-workshop survey for teachers on how often they use declarative language, as well as classroom observation of several volunteer teachers to count the number of declarative language statements used pre and post-workshop during their teaching)
- How does the use of declarative language impact students' time to task? (study design could include classroom observations of time to task before the workshop when teacher is mostly using imperative language, and post-workshop observations where the teacher is endeavouring to use mostly declarative language)

- How does the use of declarative language increase emotional literacy? (study design could include a pre-workshop survey and a second survey six months later for students on emotional literacy)

Capstone Limitations

PDA is “much discussed and described but little researched” (Christie, Duncan, Fidler, & Healy, 2012, p. 182). The main limitation of this capstone was the lack of research on pathological demand avoidance. Outside of a core group of researchers in the UK, there is little research being done on PDA, and particularly no Canadian research. Because of this, a second limitation was not having access to Canadian statistics or data on the prevalence of PDA. As such, it is impossible to say with certainty that PDA is not well-known in Canadian schools, however, anecdotal observations suggest that this is the case. A third limitation is that this capstone was not able to test a hypothesis since it was simply a review of the literature surrounding PDA, rather than a full research study.

Conclusions

Pathologically demand avoidant children can be some of the most challenging students to work with, yet challenging students often end up being the most rewarding. Through using the specific strategies outlined in this capstone paper, schools can be better equipped to meet the needs of students with PDA to ensure that their school experiences are safe, successful, and enjoyable. As educators, we have a duty to meet the needs of all students, including PDA children. Elizabeth Newson perhaps said it best in her original publication on the PDA profile: “It is essential that the extraordinary special needs of this small group of children should be generally recognized and generously met” (Newson, 1989, p. 29). My hope is that this capstone

will have made a small contribution to the ability of British Columbian educators to meeting the needs of this extraordinary group of children.

References

- Alessandri, M. & Schneider, H. (2018). Autism and autism spectrum disorders, history of. In E. Braaten (Ed.), *The SAGE encyclopedia of intellectual and developmental disorders* (pp. 120-124). Thousand Oaks, CA: SAGE Publications. doi: 10.4135/9781483392271.n45
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Washington, DC: Author.
- Asperger, H. (1991). 'Autistic psychopathy' in childhood. In U. Frith (Ed.), *Autism and Asperger Syndrome* (pp. 37-92). Cambridge: Cambridge University Press.
doi:10.1017/CBO9780511526770.002
- Autism Canada. (2018). Diagnostic criteria – DSM-5. Retrieved from <https://autismcanada.org/about-autism/diagnosis/diagnostic-criteria-dsm-5/>
- Autism Society. (2016). DSM-IV diagnostic classifications. Retrieved from <http://www.autism-society.org/dsm-iv-diagnostic-classifications/>
- BC Ministry of Education. (2016). Special education services: A manual of policies, procedures and guidelines [PDF]. Retrieved from https://www2.gov.bc.ca/assets/gov/education/administration/kindergarten-to-grade-12/inclusive/special_ed_policy_manual.pdf
- BC Ministry of Education. (2017). Student statistics - 2016/17 [PDF]. Retrieved from http://www.bced.gov.bc.ca/reports/pdfs/student_stats/prov.pdf
- BC Ministry of Education. (2018). Standards for the education, competence and professional conduct of educators in BC. Retrieved from <https://www.bcteacherregulation.ca/Standards/StandardsDevelopment.aspx>

BC Ministry of Education, Governance and Legislation Branch. (2018a). Individual education plan order [PDF]. Retrieved from

https://www2.gov.bc.ca/assets/gov/education/administration/.../e/m638_95.pdf

BC Ministry of Education, Governance and Legislation Branch. (2018b). Special needs students order [PDF]. Retrieved from

https://www2.gov.bc.ca/assets/gov/education/administration/...policy/.../m150_89.pdf

BC Ministry of Education, Special Programs Branch. (2000). Teaching students with autism: A resource guide for schools [PDF]. Retrieved from

<https://www2.gov.bc.ca/assets/gov/education/kindergarten-to-grade-12/teach/teaching-tools/inclusive/autism.pdf>

BCTF/CUPE. (2009). Roles and responsibilities of teachers and teacher assistants/education assistants [PDF]. Retrieved from

<https://bctf.ca/uploadedFiles/Public/Issues/InclusiveEd/RolesAndResponsibilitiesTeachersTAs.pdf>

Brandibas, G., Jeunier, B., Clanet, C., & Fourasté, R. (2004). Truancy, school refusal and anxiety. *School Psychology International*, 25(1), 117–126.

<https://doi.org/10.1177/0143034304036299>

Broder-Fingert, S., Walls, M., Augustyn, M., Beidas, R., Mandell, D., Wiltsey-Stirman, S., ...

Feinberg, E. (2018). A hybrid type I randomized effectiveness-implementation trial of patient navigation to improve access to services for children with autism spectrum

disorder. *BMC Psychiatry*, 18(1), 79–89. <https://doi.org/10.1186/s12888-018-1661-7>

- Calabrese, R., Patterson, J., Liu, F., Goodvin, S., Hummel, C., & Nance, E. (2008). An appreciative inquiry into the Circle of Friends Program: The benefits of social inclusion. *International Journal of Whole Schooling*, 4(2), 20–48.
- Camley, C. (2016). Special needs funding in BC schools – it’s not what you think. Retrieved from <https://equitableaccesstoeducation.wordpress.com/2016/06/25/special-needs-funding-in-bc-schools-its-not-what-you-think/>
- Carlile, J. (2009). Helping your child with PDA to play: Eight strategies for supporting a child with Pathological Demand Avoidance Syndrome at home. *Good Autism Practice*, 10(2), 57–68.
- Christie, P. (2007). The distinctive clinical and educational needs of children with pathological demand avoidance syndrome: Guidelines for good practice. *Good Autism Practice*, 1–11.
- Christie, P., Duncan, M., Fidler, R., & Healy, Z. (2012). *Understanding pathological demand avoidance syndrome in children*. London, UK: Jessica Kingsley Publishers.
- Circle of Friends – The Path to Inclusion. (2016). Program description. Retrieved from <https://www.circleofriends.org/program-description>
- Constantino, J. N., & Charman, T. (2016). Diagnosis of autism spectrum disorder: Reconciling the syndrome, its diverse origins, and variation in expression. *The Lancet Neurology*, 15(3), 279–291. [https://doi.org/10.1016/S1474-4422\(15\)00151-9](https://doi.org/10.1016/S1474-4422(15)00151-9)
- Craske, M. G., & Stein, M. B. (2016). Anxiety. *The Lancet*, 388(10063), 3048-3059. doi:[http://dx.doi.org.proxy.cityu.edu/10.1016/S0140-6736\(16\)30381-6](http://dx.doi.org.proxy.cityu.edu/10.1016/S0140-6736(16)30381-6)
- DeFilippis, M. (2018). Depression in children and adolescents with autism spectrum disorder. *Children*, 5(9), 112. <https://doi.org/10.3390/children5090112>

Dua, V. (2003). Standards and guidelines for the assessment and diagnosis of young children with autism spectrum disorder in British Columbia [PDF]. Retrieved from

http://www.phsa.ca/autism-site/Documents/asd_standards_0318.pdf

Fidler, R., & Christie, P. (2019). *Collaborative approaches to learning for pupils with PDA*. London, UK: Jessica Kingsley Publishers.

Fountain, C., King, M. D., & Bearman, P. S. (2010). Age of diagnosis for autism: Individual and community factors across 10 birth cohorts. *Journal of Epidemiology and Community Health, 65*(6), 503–510.

Gillberg, C. (2014). Commentary: PDA - public display of affection or pathological demand avoidance? - reflections on O’Nions et al. (2014). *Journal of Child Psychology and Psychiatry and Allied Disciplines, 55*(7), 769–770. <https://doi.org/10.1111/jcpp.12275>

Gillberg, C., Gillberg, I. C., Thompson, L., Biskupsto, R., & Billstedt, E. (2015). Extreme (“pathological”) demand avoidance in autism: A general population study in the Faroe Islands. *European Child and Adolescent Psychiatry, 24*(8), 979–984.

<https://doi.org/10.1007/s00787-014-0647-3>

Gore Langton, E., & Frederickson, N. (2016). Mapping the educational experiences of children with pathological demand avoidance. *Journal of Research in Special Educational Needs, 16*(4), 254–263. <https://doi.org/10.1111/1471-3802.12081>

Government of BC. (2002). K-12 funding - special needs. Retrieved from

<https://www2.gov.bc.ca/gov/content/education-training/administration/legislation-policy/public-schools/k-12-funding-special-needs>

Green, J., Absoud, M., Grahame, V., Malik, O., Simonoff, E., Le Couteur, A., & Baird, G. (2018). Pathological demand avoidance: Symptoms but not a syndrome. *The Lancet*

Child and Adolescent Health, 2, 455–464.

<https://doi.org/http://dx.doi.org/10.1016/S2352-4642%2818%2930044-0>

Harris, J. C. (2016). The origin and natural history of autism spectrum disorders. *Nature Neuroscience*, 19(11), 1390-1391.

Hurtig, T., Kuusikko, S., Mattila, M. L., Haapsamo, H., Ebeling, H., Jussila, K., et al. (2009). Multi-informant reports of psychiatric symptoms among high-functioning adolescents with Asperger syndrome or autism. *Autism*, 13(6), 583–598.

Kanner, L. (1943). Autistic disturbances of affective contact. *The Nervous Child*, 2, 217-250.

Kendall, P. C., Safford, S., Flannery-Schroeder, E., & Webb, A. (2004). Child anxiety treatment: Outcomes in adolescence and impact on substance use and depression at 7.4-year follow-up. *Journal of Consulting and Clinical Psychology*, 72(2), 276-287.

[doi:http://dx.doi.org.proxy.cityu.edu/10.1037/0022-006X.72.2.276](http://dx.doi.org.proxy.cityu.edu/10.1037/0022-006X.72.2.276)

Kern Koegel, L. (2018, October). *Practical ways to decrease disruptive behaviour*. Paper presented at Setting the Stage for Success: Positive Behavior Support in School, Home and Community, Vancouver, BC. Retrieved from <https://www.actcommunity.ca/education/act-events/positive-behaviour-support-in-school-home-and-community>

Kincaid, D., Dunlap, G., Kern, L., Lane, K. L., Bambara, L. M., Brown, F., ... Knoster, T. P. (2016). Positive behavior support: A proposal for updating and refining the definition. *Journal of Positive Behavior Interventions*, 18(2), 69–73.

<https://doi.org/10.1177/1098300715604826>

- Kulusic, T., Long, K. De, Appleby, D., Gardiner, C., Konowalchuk, S., Lalji, F., & Schuman, C. (2014). *A parent's handbook on inclusive education*. New Westminster, BC: Inclusion BC.
- Kupferstein, H. (2018). Evidence of increased PTSD symptoms in autistics exposed to applied behavior analysis. *Advances in Autism, 4*(1), 19-29.
doi:<http://dx.doi.org.proxy.cityu.edu/10.1108/AIA-08-2017-0016>
- Lasgaard, M., Nielsen, A., Eriksen, M. E., & Goossens, L. (2010). Loneliness and social support in adolescent boys with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 40*(2), 218-26. doi:<http://dx.doi.org.proxy.cityu.edu/10.1007/s10803-009-0851-z>
- Lyons, V., & Fitzgerald, M. (2007). Asperger (1906–1980) and Kanner (1894–1981), the two pioneers of autism. *Journal of Autism and Developmental Disorders, 37*, 2022-2023.
- Mazurek, M. O., Lu, F., Symecko, H., Butter, E., Bing, N. M., Hundley, R. J., et al. (2017). A prospective study of the concordance of DSM-IV and DSM-5 diagnostic criteria for autism spectrum disorder. *Journal of Autism and Developmental Disorders, 47*(9), 2783-2794. doi:<http://dx.doi.org.proxy.cityu.edu/10.1007/s10803-017-3200-7>
- Morgan, D. (2018). Applied behavior analysis. In B. Frey (Ed.), *The SAGE encyclopedia of educational research, measurement, and evaluation* (pp. 101-104). Thousand Oaks, CA: SAGE Publications, Inc. doi: 10.4135/9781506326139.n48
- Murphy, L. (2010). The critical importance of declarative language input for children with ASD. *Autism Spectrum Quarterly, 8*-10.
- National Autistic Society. (2017). What is pathological demand avoidance (PDA)? Retrieved from <https://www.autism.org.uk/about/what-is/pda.aspx>

- Newson, E. (1989). Pathological demand avoidance syndrome: Diagnostic criteria and relationship to autism and other developmental coding disorders. University of Nottingham.
- Newson, E. (1996). Pathological demand avoidance syndrome: A statistical update. In *Annual International Durham Conference on Autism: Therapeutic intervention in autism: Perspectives from research and practice* (pp. 1–20). Sunderland, UK: University of Sunderland.
- Newson, E. (2016). Education and handling guidelines for children with Pathological Demand Avoidance Syndrome [PDF]. Retrieved from <https://www.autismeastmidlands.org.uk/wp-content/uploads/2016/10/Educational-and-handling-Guidelines.pdf>
- Newson, E., & Le Maréchal, K. (1998). Pathological demand avoidance syndrome: Discriminant functions analysis demonstrating its essential differences from autism and Asperger's syndrome. In *Annual International Durham Conference on Autism: Psychobiology of autism: Current research and practice*. Sunderland, UK: University of Sunderland.
<https://doi.org/10.1007/bf03344014>
- Newson, E., Le Maréchal, K., & David, C. (2003). Pathological demand avoidance syndrome: A necessary distinction within the pervasive developmental disorders. *Archives of Disease in Childhood*, 88(7), 595–600. <https://doi.org/10.1136/adc.88.7.595>
- Ogundele, M. O. (2018). Behavioural and emotional disorders in childhood: A brief overview for paediatricians. *World Journal of Clinical Pediatrics*, 7(1), 9–26.
<https://doi.org/10.5409/wjcp.v7.i1.9>
- O’Nions, E., Christie, P., Gould, J., Viding, E., & Happé, F. (2014). Development of the “Extreme Demand Avoidance Questionnaire” (EDA-Q): Preliminary observations on a

- trait measure for pathological demand avoidance. *Journal of Child Psychology and Psychiatry and Allied Disciplines*, 55(7), 758–768. <https://doi.org/10.1111/jcpp.12149>
- O’Nions, E., Gould, J., Christie, P., Gillberg, C., Viding, E., & Happé, F. (2015). Identifying features of ‘pathological demand avoidance’ using the Diagnostic Interview for Social and Communication Disorders (DISCO). *European Child and Adolescent Psychiatry*, 25(4), 407–419. <https://doi.org/10.1007/s00787-015-0740-2>
- O’Nions, E., & Noens, I. (2018). Commentary: Conceptualising demand avoidance in an ASD context – a response to Osman Malik & Gillian Baird (2018). *Child and Adolescent Mental Health*, 23(4), 389–390. <https://doi.org/10.1111/camh.12287>
- O’Nions, E., Viding, E., Floyd, C., Quinlan, E., Pidgeon, C., Gould, J., & Happé, F. (2018). Dimensions of difficulty in children reported to have an autism spectrum diagnosis and features of extreme/‘pathological’ demand avoidance. *Child and Adolescent Mental Health*, 23(3), 220–227. <https://doi.org/10.1111/camh.12242>
- PDA Society. (2018). About PDA. Retrieved from <https://www.pdasociety.org.uk/what-is-PDA/about-pda>
- PDA Society UK. (2016). Pathological demand avoidance syndrome: A reference booklet for health, education and social care practitioners. Retrieved from <https://www.pdasociety.org.uk/professionals/awareness-matters-booklet>
- Powers, C. J., & Bierman, K. L. (2013). The multifaceted impact of peer relations on aggressive–disruptive behavior in early elementary school. *Developmental Psychology*, 49(6), 1174–1186. doi:<http://dx.doi.org.proxy.cityu.edu/10.1037/a0028400>

Provincial Outreach Program for Autism and Related Disorders. (n.d.). POPARD: Provincial Outreach Program for Autism and Related Disorders. Retrieved from

<http://www.autismoutreach.ca/>

Public Health Agency of Canada. (2018). Autism spectrum disorder among children and youth in Canada 2018. Retrieved from [https://www.canada.ca/en/public-health/services/publications/diseases-conditions/autism-spectrum-disorder-children-](https://www.canada.ca/en/public-health/services/publications/diseases-conditions/autism-spectrum-disorder-children-youth-canada-2018.html#a3-5)

[youth-canada-2018.html#a3-5](https://www.canada.ca/en/public-health/services/publications/diseases-conditions/autism-spectrum-disorder-children-youth-canada-2018.html#a3-5)

Queen's Printer. (2018). School act. Retrieved from

http://www.bclaws.ca/civix/document/id/complete/statreg/96412_02

Resource Management and Executive Financial Office. (2018). Operating grants manual 2018/19 [PDF]. Retrieved from

<https://www2.gov.bc.ca/assets/gov/education/administration/resource-management/k12funding/18-19/18-19-operating-grants-manual.pdf>

Russell, G., Steer, C., & Golding, J. (2011). Social and demographic factors that influence the diagnosis of autistic spectrum disorders. *Social Psychiatry and Psychiatric Epidemiology*, 46(12), 1283–1293. <https://doi.org/10.1007/s00127-010-0294-z>

Shields, K. (2018). Use the power of your school-based team to help yourself and your students.

Teacher Magazine, 31(1), 11.

Smith, T., & Eikeseth, S. (2011). O. Ivar Lovaas: Pioneer of applied behavior analysis and intervention for children with autism. *Journal of Autism and Developmental Disorders*, 41(3), 375-8. doi:<http://dx.doi.org.proxy.cityu.edu/10.1007/s10803-010-1162-0>

Trundle, G., Craig, L. A., & Stringer, I. (2017). Differentiating between pathological demand avoidance and antisocial personality disorder: A case study. *Journal of Intellectual*

- Disabilities and Offending Behaviour*, 8(1), 13–27. <https://doi.org/10.1108/JIDOB-07-2016-0013>
- Tsai, L. Y., & Ghaziuddin, M. (2014). DSM-5 ASD moves forward into the past. *Journal of Autism and Developmental Disorders*, 44(2), 321-30.
doi:<http://dx.doi.org.proxy.cityu.edu/10.1007/s10803-013-1870-3>
- Wade, S. (n.d.). *Connecting with your child through declarative language*. Burnaby, BC: Kids First Pediatric Therapy.
- Walker, G. R. (1993). Noncompliant behaviour of people with mental retardation. *Research in Developmental Disabilities*, 14, 87-105.
- White, S. W., & Roberson-Nay, R. (2009). Anxiety, social deficits, and loneliness in youth with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 39(7), 1006–1013. <https://doi.org/10.1007/s10803-009-0713-8>
- Wing, L., Gould, J., & Gillberg, C. (2011). Autism spectrum disorders in the DSM-V: Better or worse than the DSM-IV? *Research in Developmental Disabilities*, 32(2), 768-773.
- Woods, R. (2017). Pathological demand avoidance: My thoughts on looping effects and commodification of autism. *Disability and Society*, 32(5), 753–758.
<https://doi.org/10.1080/09687599.2017.1308705>
- World Health Organization. (2016). International statistical classification of diseases and related health problems, 10th revision. Retrieved from <https://icd.who.int/browse10/2016/en>
- Zuckerman, K. E., Sinche, B., Mejia, A., Cobian, M., Becker, T., & Nicolaidis, C. (2014). Latino parents' perspectives on barriers to autism diagnosis. *Academic Pediatrics*, 14(3), 301–308. <https://doi.org/10.1016/j.acap.2013.12.004>

Appendix A

DSM-5 Diagnostic Criteria

AUTISM SPECTRUM DISORDER 299.00 (F84.0)

A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history (examples are illustrative, not exhaustive, see text):

1. Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.
2. Deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.
3. Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.

Specify current severity:

Severity is based on social communication impairments and restricted repetitive patterns of behavior (see Table 2 [Severity levels for autism spectrum disorder]).

B. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history (examples are illustrative, not exhaustive; see text):

1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases).

2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns or verbal nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat food every day).
3. Highly restricted, fixated interests that are abnormal in intensity or focus (e.g, strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interest).
4. Hyper- or hyporeactivity to sensory input or unusual interests in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).

C. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life).

D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.

E. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level (American Psychiatric Association, 2013, p. 50-51).

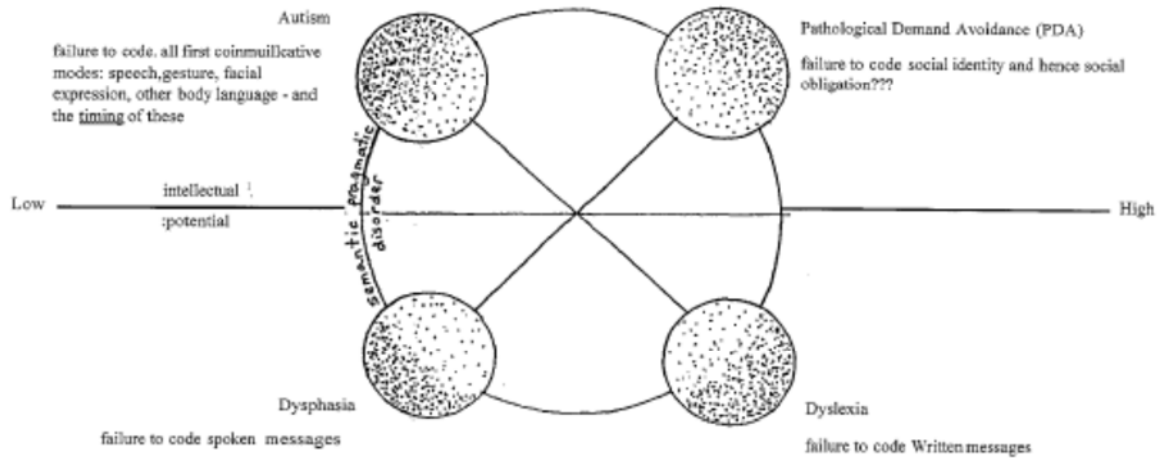
Appendix B

Pervasive Developmental Coding Disorders

Table 1

Schema for the

PERVASIVE DEVELOPMENTAL CODING DISORDERS



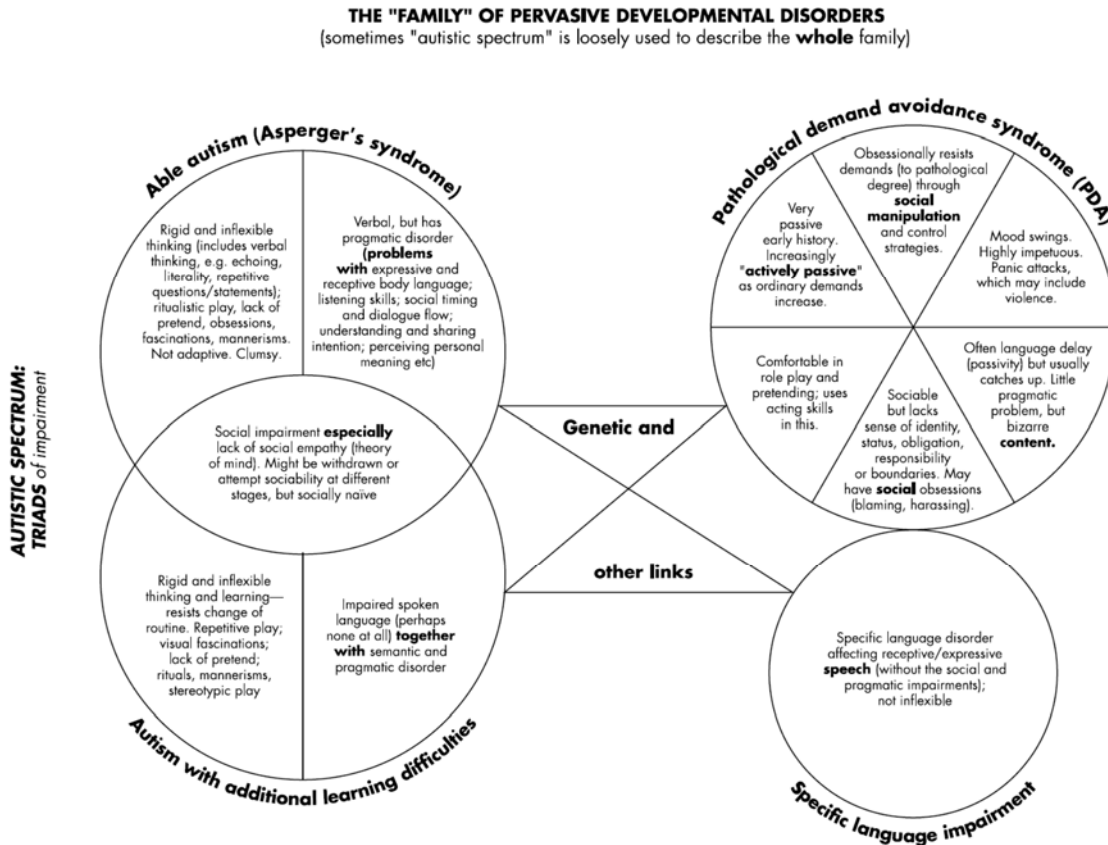
Note: interconnections imply the possibility of overlap of two or more disorders in particular children, as well as the possibility of a focus somewhere between two disorders. Speckles indicate possibility of greater or lesser severity.

Elizabeth Newson
Nottingham University
March 1986

(Newson, 1989, p. 30)

Appendix C

The “Family” of Pervasive Developmental Disorders



(Newson, Le Maréchal, & David, 2003, p. 599)

Appendix D

Priority Rating Chart

Student Name: Class, age:		
How important is it that the student...	Priority level (high/medium/low)	Comments, rationale, plan
<i>Does not hurt herself or others</i>	<i>High</i>	<i>This is non-negotiable. It will be explained to the student that staff will intervene should this happen and that it will be discussed with her parents.</i>
<i>Stays seated throughout lessons</i>	<i>Medium</i>	<i>Regular movement breaks will be put in place during lessons to give the student valid reasons to leave her seat. These will be gauged by her support staff who can respond flexibly to her needs.</i>
<i>Brings own pencil case and supplies</i>	<i>Low</i>	<i>No expectation of this. Equipment to be subtly provided without comment.</i>
Completed in consultation with:	Date:	Next review of the above planned for:

(Fidler & Christie, 2019, p. 41-42, 155)

Appendix E

The Circle of Friends Program

The Circle of Friends Program (CoF) includes the following:

- CoF organizes a different group of non-disabled peers (two to four) around a student with special needs, multiple days per week, enabling students with disabilities to form multiple friendships over the school year. Our model of inclusion is appropriate to all grade levels.
- These small CoF groups meet weekly throughout the school year at a variety of locations, fully woven into the fabric of the campus.
- CoF provides on-going training to non-disabled peers throughout the year. They are shown how to model and shape appropriate language skills.
- Weekly phone calls provide the opportunity for students with special needs to develop the life skill of speaking on the phone. They accustom themselves to dialing, leaving messages, asking for friends, and talking to peers when not face-to-face.
- Monthly large group activities, on campus or within the community, are encouraged as part of Circle of Friends. These gatherings (e.g., dances, holiday parties and meals) offer additional opportunities to socialize and bring all CoF participants together to have fun and get to know each other better. This allows for community members to see how effortlessly students with and without special needs interact.
- A CoF Student Officer Board (under the supervision of school CoF Advisors) meets weekly to organize and run the program, planning community activities, “Ability Awareness” presentations, and a year-end Friendship Celebration.
- During “Ability Awareness” presentations, students in CoF share with classmates an understanding of disabilities and the unique gifts and talents we each possess. As peers

talk to peers about these issues that matter, the campus climate is positively impacted and becomes sensitized to personal differences. More considerate and mindful behavior is inspired.

- Meetings for the parents of students with special needs are recommended annually. This is a time and space for parents to join in voicing their concerns, challenges and experiences, while sharing knowledge. It is a sanctuary that fosters true support and trust.

(Circle of Friends – The Path to Inclusion, 2016)

Appendix F

Professional Development Workshop on Declarative Language

Suggested Audience: this workshop is appropriate for both elementary and secondary schools and should include all school staff (classroom teachers, resource teachers, school counsellors, educational assistants, and administrators)

Time Needed: approximately 3 hours (designed to be presented during a morning or an afternoon on a professional development day)

Resources Required:

- Photocopy and cut up the Matching Activity Printable; place into envelopes for one envelope per table of participants
- Photocopies of Sentence Starters Printable (enough for one per participant, double-sided)
- Flip chart paper with the following categories written at the top – during the break, post these around the room for Practice activity: Sharing an opinion / Announcing an event / Celebrating success / Making an observation / Reflecting on past experiences / Problem solving
- Flip chart markers (a few per piece of paper)
- Masking tape
- Audiovisual needs: computer with speakers connected to projector and internet

Workshop Outline:

Introduction (5 minutes)

- A brief introduction to the presenter (who they are, credentials)
- A brief introduction to the purpose of this workshop: to learn about a strategy called declarative language

- Ask: has anyone heard of declarative language? (note anyone who has heard of it as they can be used as “experts” later in the workshop)
- Introduce the icebreaker activity

Icebreaker Activity (10 minutes)

- Play a game of “Simon Says” to introduce the concept of imperative language (e.g., “Simon says touch your nose” and all participants touch their nose, but if you just say “touch your nose” then participants who touch their nose are “out” and have to sit down)
- End the game by having all workshop participants sit down at their preferred table (“Simon says sit down at your table”)

What is imperative language? (20 minutes)

- Discuss the icebreaker activity asking the following questions: how effective was this activity at getting you to complete tasks? Who had control in the game? What motivated you to follow the commands given?
- Give the definition of imperative language: questions or commands to get another person to complete a task or give a specific response
- Ask: how many commands do you think you give in one day to your students? (ask for hands up for more than 10, more than 20, etc. until no more hands go up)
- Ask: how often do you ask questions to your students that you already know the answer to in any given day? (ask for hands up for more than 10, more than 20, etc. until no more hands go up)
- Ask for volunteers to share examples of how they typically use imperative language in their everyday practice

- Ask: Why do we use imperative language? (expected answers: because it's a fast way to get students to do something, because it's how we were talked to by teachers/parents, because we were taught to ask questions by teacher education programs)
- Ask: what type of information do you get by asking a question that you already know the answer to? (expected answer: that the student also knows the answer)
- Ask: does asking questions that you already know the answer to tell you anything about the student's thought process? (expected answer: not really!)
- Ask: who has the power in commands? (expected answer: the person giving the command)
- Ask: what would have happened in the Simon Says game if someone had said "no" to a command, rather than followed it? (expected answer: a power struggle may have ensued)
- Imperative language creates the perfect conditions for power struggles since one person has all of the power; all a student has to do is say "no" and your lesson is derailed by an argument
- Ask: what if I told you there was another way to get students to complete tasks or show their learning that does not include commands or questions you already know the answer to, and this other way prevents power struggles, increases intrinsic motivation, and builds skills in your students for problem solving and emotional literacy? (rhetorical question, answers not really expected)
- This other way is called declarative language

What is declarative language? (25 minutes)

- Give the definition of declarative language: language that declares what you are observing, what you are experiencing, or what you see your students doing

- Declarative language is part of a newer autism therapy called “Relationship Development Intervention” (or RDI)
- From rdiconnect.com/about-rdi: “RDI® is a next generation approach to autism and developmental disability intervention that is based on the latest scientific research into the human brain”
- The goal of RDI is to develop meaningful relationships between the autistic child and their loved ones, and through those relationships to help the child develop dynamic thinking
- While RDI is targeted towards autistic children, many RDI strategies like declarative language work to develop relationships and dynamic thinking with all children, not just those who are autistic
- There are three types of declarative language (review each of these with the examples given, and ask for audience input for other examples):
 - Declaring what you are doing: “I’m going to write today’s schedule on the board” / “I’m moulding the clay this way so that it keeps its shape better” / “I write the math equation like this so that it is clear what my reasoning is”
 - Declaring what you are experiencing: “I’m finding it quite loud in this room” / “I am so excited to hear this next group’s presentation!” / “I’m noticing that I feel a bit nervous when I talk about this topic”
 - Declaring what you see your students doing: “Everyone is working so quietly!” / “It looks like some of you are having problems getting started on this activity” / “Sam, I notice you are doing this task much faster than usual!”

What does declarative language sound like? (15 minutes)

- Show YouTube video (2.5 minutes), and have participants note any time they hear declarative language: https://www.youtube.com/watch?v=IeE4bKG_m48
- Debrief after the video, ensuring they noticed the following declarative language statements:
 - We're getting it all clean
 - Now we can clean the outside of the bowl like this
 - More rinse, (correction) we can rinse it some more
 - Now we just need to set it to dry
 - It dries over there
 - It dries on the orange towel
- Ask: were there any statements the mother made in the video that were not declarative? (expected answer: "it's your turn")
- Ask: How could that statement be made declarative? (possible answer: "I wonder if you would like to have a turn?")
- Note that declarative language doesn't always require a verbal response – the adult is sometimes the only one talking, but the child is listening to everything you say and learning more about how you see the world

Why should we use declarative language? (10 minutes)

- Declarative language is all about modelling how to communicate with others authentically to be able to develop better relationships
- Declarative language invites shared experiences: imperative language teaches that there is a right and wrong answer, while declarative language invites the student to help figure out what the answer is

- Declarative language prevents power struggles: while imperative language allows the opportunity for a child to say “no,” declarative language isn’t asking for a yes or a no, so power struggles are avoided
- Declarative language increases intrinsic motivation: while imperative language gets the student to complete a task, their motivation is typically to fulfil your request; in contrast, declarative language increases their intrinsic motivation since they are choosing to complete a task (or at least think that they are choosing since you as the adult can be strategic in how you phrase a declarative statement!)
- To teach problem solving skills: imperative language tells the student to do something in a particular way, while declarative language invites the student to figure out how to solve a problem; the adult’s role in declarative language problem solving is to model problem solving skills by sharing their experiences of solving similar problems
- To increase emotional literacy: imperative language is all about getting something done, while declarative language invites adults to share their emotional experiences and give names to emotions, thus modelling for students better emotional literacy

Break (15 minutes)

Matching Activity (15 minutes)

- Distribute envelopes of pre-prepared imperative/declarative statements to each table of participants
- Have them sort the statements into two categories: imperative and declarative
- Ask each group to share one imperative statement and one declarative statement – continue sharing until all statements have been shared to check for understanding

Practice Activity (40 minutes)

- As with any skill, practice is essential for mastery; the last part of this workshop will focus on lots of practice in using declarative language
- Distribute the sentence starters handout and have teachers work in small groups (about three people per group) to create three examples of each category of declarative language
- After about 30 minutes, have teachers write their examples on the large flip chart paper labelled with each category

Gallery Walk (10 minutes)

- Have teachers walk around and look at the different statements created by their colleagues
- At this point, encourage participants to complete the “Strategy Challenge” at the end of the handout if they haven’t already done so – this is a place where individuals can challenge themselves to start using declarative language in their everyday practice

Questions? (10 minutes)

- Leave time for questions

Closing (5 minutes)

- Ask: would anyone like to share how they plan to challenge themselves to use declarative language the next time they see their students?
- Thank the participants for their participation and attention
- Give a declarative language statement of your experience with the workshop (e.g., “I really enjoyed presenting today to all of you”)
- Tell staff that the flip chart paper examples will be left posted in a common area (e.g., staff room) for staff to refer back to as they begin to try using more declarative language in their classrooms

Follow-up:

- Post the flip chart paper and leave behind a few extra copies of the sentence starter handout
- Provide contact information for presenter to the school in case participants have any follow-up questions

Printable for Matching Activity

<i>Imperative Statements</i>	<i>Declarative Statements</i>
Sit down in that chair.	I wonder where we should sit?
Start your math assignment.	I love math!
Tomorrow you will go to an assembly.	I think we are having an assembly tomorrow.
You had fun today, didn't you?	We had a great time today!
Give your friend a turn.	I notice that your friend wants a turn.
Just do what you did to fix it the last time it broke.	Last time this stopped working we checked the batteries.
Go get the tape and fix that.	We need tape to fix it.
Go outside for recess.	I notice that all of the kids are going outside for recess.
Why do we need to be quiet during an assembly?	I wonder what would happen if everyone talked during an assembly?
Go put on your coat.	I notice that all the kids are putting on their coats.

Declarative Language Sentence Starters Handout

Sentence starters that are useful for declarative language statements include:

- Sentences that start with “I...” since this shares your experience
 - “I wonder...”
 - “I notice...”
- Sentences that start with “We...” since this invites the child into the experience
- Questions are allowed, however they should not be asked with a specific response in mind, but rather to invite ideas and share experiences
- Note: avoid sentences that start with “you” since this typically precedes a demand (e.g., “you need to do this”)

Type of declarative language	Example	Your examples
Sharing an opinion	<i>I love math!</i>	1. 2. 3.
Announcing an event	<i>I think we are having an assembly tomorrow.</i>	1. 2. 3.
Celebrating success	<i>We had a great time today!</i>	1. 2. 3.

Type of declarative language	Example	Your examples
Making an observation	<i>I notice that your friend wants a turn.</i>	1. 2. 3.
Reflecting on past experiences	<i>Last time this stopped working we checked the batteries.</i>	1. 2. 3.
Problem solving	<i>We need tape to fix it.</i>	1. 2. 3.

Strategy Challenge

The next time I see my students, I will use declarative language to...